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**SO YOU THINK IT'S INCLUSION...
THINK AGAIN:**

**A QUANTITATIVE ANALYSIS OF STAKEHOLDER PERCEPTIONS
IN COMMUNITY YOUTH ORGANIZATIONS**

by

MARY MCALLISTER SHEA

A dissertation submitted in partial fulfillment
of the requirements for the degree of

Doctor of Education
University of San Diego

April 2006

Dissertation Committee

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ABSTRACT

Over the last thirty years, a cultural transformation has occurred in public schools as students with disabilities have slowly moved from segregated sites and special day classes to more inclusive classroom environments. Although this change has largely been driven by legislative mandate, including the requirement that students be supported in the least restrictive environment possible, the benefits of inclusion have been exceedingly well documented in the literature. Unfortunately, the inclusiveness seen within schools has not extended to the provision of out-of-school programs, and as a result, sixteen years after the passage of the Americans with Disabilities Act, children with disabilities are still grossly under-represented in out-of-school time programs throughout the nation.

As provider organizations slowly begin to adopt more inclusive practices in their out-of-school programs, it is imperative for them to understand, from the perspective of their stakeholders, the extent to which they are making progress in creating a more inclusive environment for children with disabilities. As such, this study examined and compared the perceptions of four stakeholder groups associated with five youth development organizations in San Diego County, defined as the *leadership*, *staff*, and *parents of children with, and without disabilities*, to see how far along the developmental continuum each of the groups felt their particular organization was in terms of including children with disabilities. A total of 216 stakeholders responded to the *Organizational Developmental Model of Inclusion for Individuals with Disabilities*, a self-reflective survey tool that used a five-point Likert scale together with 50 statements that represented conditions and practices within their organization.

Results suggest that there were significant differences in the perceptions of these four stakeholder groups, with *leadership* typically feeling that their organization was further along the continuum than the other groups. Similarly, when leadership and staff were combined and parents were combined, all five *organizations* perceived that they were further along the continuum than did their *consumers*. As such, the results of this study support the use of a self-reflective tool before and during the change process, so that organizations can assure that their behavior represents genuine and not merely symbolic inclusion.

DEDICATION

My mother and father who lived through the Great Depression and served their country in World War II, taught me to dream and helped me believe that there wasn't anything I couldn't do if I set my mind to it and worked hard toward that end. My husband has been an example of someone who worked tirelessly to realize his dreams and unselfishly support his family so that they too might realize their dreams. My two beautiful and wonderful daughters have brought me so much joy and hope and have always been a constant source of strength and support. My faith in God has been my rock in all times and places.

It is with deep gratitude and immense love that I dedicate this dissertation to my late father, Austin McAllister and my mother, Jeanne McAllister who taught by example and unselfishness and who had the energy to do it seven times over for each of their children. I also dedicate this dissertation to my husband, Paul Shea, for quietly supporting me during these many long years and allowing me the time and space to pursue my work and my professional goals and for never doubting that I would finish. And, to my truly exceptional and lovely daughters Kelly and Erin Shea, who have given me their unconditional gifts of love and support throughout their young lives and always gave me a reason to wake up with a smile, celebrate their successes and accomplishments, and to count my blessings.

ACKNOWLEDGEMENTS

I could not have accomplished this without the encouragement and support of a number of people. Some are near, some are far away, some are no longer here, but all of them have supported me in this journey.

I would like to acknowledge Fred Galloway, my chair. Little did I know that when we started this journey together several years ago that he would be the “perfect chair” for my dissertation committee. He was, in fact, the last in a line of possible committee chairs because I was one of those “on again – off again” students whose efforts to complete was derailed because of a demanding new job as co-founder of a not-for-profit organization and several personal moves to Northern California, Washington, and finally my home in Oregon. Fred helped me frame my ideas for research and encouraged me to tackle quantitative research, something I ended up loving. He had very high writing standards and seemed to demand near perfection at every step of the process and wouldn’t let me push through a draft or paragraph that wasn’t ready. Finally, Fred really took time to appreciate my study and the possible impact it could have in a professional field where there has been little or no research. I am eternally grateful to Dr. Galloway for his time, energy, and his investment and commitment to me as a doctoral student.

I would also like to acknowledge Paula Cordeiro, the Dean of the School of Education who made such an indelible impression on me when she came to USD as the new Dean. She had such a clear vision for the School of Education which needed new energy and a broader faculty. Paula had a passion for teaching and all I needed was one class with her to know that she was a real change agent. She was an inspiration instantly and I am so

grateful that while she had agreed to serve on my committee years ago, she kept that commitment all those years later, even though her responsibilities had quadrupled.

I am so grateful to Caren Sax, who started the doctoral program with me almost a decade ago and became a friend, mentor, early encourager, and who shared the same passion I had for working with people with disabilities and their families. She is so competent and articulate and someone I knew I wanted to model academically and professionally. Caren, who is a very critical thinker always had time to meet for coffee and seemed to have a gift to see through my enthusiasm to help me frame how and what I could do with my energy and passion for inclusion in out-of-school time programs. She never let me down when it came to editing my work, but most of all she consistently encouraged me to persist with the process.

How can I thank Andrea Saltzman Martin who always made time for me and assisted many early mornings with understanding and managing statistical data analysis? Also thank you to Moises Baron and Ruben Mitchell whose research in examining diversity in higher education provided the framework for my study which expanded the definition of diversity to include individuals with disabilities

There are so many professionals whom I have worked with over the years, but my friend Jacqueline Siptroth influenced more than any, my transformation in the world of disability from a medical model to an empowerment model. My greatest professional joy has been to work with my colleagues at Kids Included Together -- Jan, Sara, Torrie, Dede, and Stephanie, as well as our consultants and trainers, who have all embraced a commitment to create caring communities where ALL children are valued and respected.

They have endured my journey with me and supported and encouraged me to *get it done* and now we all can celebrate those extra initials behind my name.

There are hundreds of families of children with disabilities that I have known over the years that have touched my life, but there are several parents who have particularly influenced me by sharing their hopes and dreams in their child's journey to inclusion. They include Jill Chambers, Lisa Houghtelin, Joyce Clark, Sheila Matthews and Lisa Schaerer. These women are my heroes.... They have never stopped caring for their beautiful children; nor have they stopped advocating for children with disabilities. They are wise and articulate and have a strength and resiliency that can't be described.

I want to thank the hundreds of children who over the years have touched my life and inspired me to help them find a way to experience real belonging. They include Sean and Charlie, Will and Jonathon, Jamie, Macy, Megan, and Darah, Phillip, Lucas and Matthew. Thanks to their parents for trusting me enough to allow their children to leave their traditional environments, to take risks, to make new friends, to learn new skills and learn that they had gifts to offer as well.

Finally, I want to thank my best friend and husband, Paul Shea, who for 35 years has encouraged and supported me while I balanced work and school and family, and who recently has had to tolerate my distraction and obsession with completing this process. I also want to thank my daughters, Kelly and Erin who from the time they were born brought me uncompromised joy and pride. They have grown into competent bright young women who know and believe that they can use their many talents and gifts to make a difference in the world. They are my inspiration.

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CHAPTER 1

OVERVIEW OF THE STUDY

INTRODUCTION

We long for wisdom to make the world more decent and tolerant and caring, a world where all of us figure in one another's survival. We believe that much of the wisdom needed for the task comes from reaching toward those we may have been programmed to avoid. (Perkse & Perske, 1988, p.9).

These words are expressed in the opening pages of Circle of Friends, a book about how people with disabilities and their friends enrich the lives of one another. Man is a social being and is disposed to live with a "community of others," not just family and friends. Social justice requires that as a society we create communities that are not indifferent or callused to persons who are different from us. Theologian and philosopher Paul Ricoeuer (1992) reminds us it is not enough to think about ethics and social justice, but that we must act to create "the 'good life' with and for others in just institutions" (p.172). The "others" referred to in this research proposal are the tens of thousands of children with disabilities and their families in this country that continue to experience isolation and/or discrimination when attempting to access community youth programs. These children have a right to be valued and welcomed into their communities.

In the twenty-first century, the majority of persons with disabilities continue to encounter social, psychological and economic barriers while they strive for respect, empowerment and inclusion in their communities. While there has been some improvement in the quality of their lives in recent decades, most people with disabilities continue to experience few opportunities for meaningful inclusion and many continue to

live in relative isolation (Disability Statistics Abstract, 1998). While some rehabilitation systems have attempted to provide social programs for people with disabilities, at least 50 % of respondents to the Ninth Harris Poll of Americans with Disabilities (2000) stated they lacked a full social life and most reported the desire for recreation and social activities as an unfulfilled need in their lives. If we explore the historical treatment of people with disabilities and the societal perception of people with disabilities, we can understand the isolation people with disabilities have experienced. While recognizing that civil rights legislation, a self-determination movement, as well as the empowerment of parents have improved the lives of people with disabilities in the 20th century, many challenges remain.

The proposed study will begin with a literature review identifying barriers and enablers to inclusion as defined by educators, those with the longest and broadest history of including children with disabilities. The impact of empowerment, stakeholder participation, collaboration, boundary crossing and influence of leadership in influencing sustainable inclusive communities will be described. Using the education system as a model, the study will investigate the influence of an organization's capacity for learning and the developmental process involved in organizational change as it relates to creating inclusive communities. While this study provides a framework for understanding quality of life issues for all people with disabilities, one specific developmental phase of the life cycle, childhood, will be the primary focus.

Statement of the Problem

Historically individuals with disabilities have had limited or no access to recreation, leisure activities or child care, and when it was available to them, it was frequently time

limited and segregated. The programs, while surely meeting a need for many people with disabilities, have also had an impact of supporting disenfranchisement and a distancing of people with disabilities from their natural communities. Many people without disabilities continue to have stereotyped perceptions about the capabilities of people with disabilities and what they can accomplish, often leading to withholding opportunities for learning and decision making that limits growth and development which in turn, confirms the prejudiced belief.

Not until the last two decades was there a significant attempt to improve conditions for people with disabilities in terms of increasing autonomy and their ability to plan their own futures. Mount and Zwernik (1987), McKnight (1987), and O'Brien (1986), described a philosophy of futures' planning where the individual's desires and needs drives a problem solving approach to coordinating services and connecting to community in individualized and meaningful ways. Some community-based supports and services have facilitated the welcoming of individuals with disabilities in school, work, and recreational environments, thereby increasing awareness, tolerance and acceptance of people with disabilities. Without these opportunities to grow and learn, people with disabilities will not learn new roles or experience belonging. Few organizations recognize that denying these opportunities constitutes a civil rights violation as well as a social injustice. This study proposes that the first step in raising awareness of the issue is to begin a process of individual and organizational self reflection about how the organization welcomes and supports the inclusion of individuals with disabilities. Only after that self-reflection can the organization begin to develop a plan that will move them along in the developmental process of true and respectful inclusion.

While children with disabilities and special needs are represented and visible in public schools as a result of legislative mandates, significant barriers exist for children with disabilities and special needs in after school programs (California Map to Inclusive Child Care Project, 2000). The barriers identified and described by providers include negative attitudes and perceptions, lack of training, fear of not having adequate skills or resources to support the child with a disability and a concern that including the child with a disability will somehow compromise the experience for children without disabilities. Parents who attempt to enroll their child in after school social or recreation programs are frequently denied access or told the child can participate if the parent or sibling accompanies him and/or if the parent provides an aide or personal attendant to support the child. Both of these scenarios constitute a violation of the ADA, however because there is no system of monitoring compliance, few families choose to pursue legal action and for most of them, their children continue to be excluded from community programs.

Background of the Study

People with disabilities are the group most discriminated against in America (Harris Poll, 1998). Studies have shown that people with disabilities, some 50,000,000 in America, are the poorest-educated, poorest-housed, most unemployed or underemployed (Condeluci, 1995). The development of a strong medical paradigm based on deficiency theory resulted in the creation of rehabilitation systems driven by so called experts who resorted to identifying, labeling and attempting to fix people with disabilities. The efficacy of the medical model, which drew attention to differences, has indirectly resulted in a system that has devalued and disempowered individuals with disabilities, while making many of them dependent on social services. The model facilitated the

development of segregated programs and services that failed to give real voice to people with disabilities and their families regarding their needs, interests, and goals. In a shift to an empowerment model, the 1990s began to witness a paradigm change where choice, opportunity, interdependence and community building were valued as the path to creating quality lives for individuals with disabilities.

The data provide a clear picture of the state of employment and quality of life issues for individuals with disabilities. The National Organization on Disability (Harris Poll, 2004) documented at least 65 percent of people with disabilities as unemployed or seriously underemployed and 26 percent who live in poverty, three times the average of nine percent. People with disabilities are twice as likely to drop out of high school and thousands of people with disabilities continue to spend their days in sheltered workshops, work/life skills programs or meaningless adult day programs. Quality of life assessments and personal interviews of people with disabilities cite lack of friendships and limited opportunity for relationships beyond their families and the providers who are paid to be with them (Condeluci, 1995). Often isolation and loneliness characterize their lives. Perske and Perske (1988) wrote about the sadness that many individuals with disabilities feel when they come to the realization that the only people relating to them – outside of relatives – are paid to do so. One of the benefits of recreation and social activities is that the experiences can offer friendships and relationships, occasionally even intimacy, all central in the concept of interdependence. Research in early childhood education and elementary education also confirms that the sooner children with disabilities are included in natural environments with children without disabilities, the more self confident and

socially competent they become (Lamorey & Bricker, 1993; Odom & Brown, 1993; Staub, Spaulding, Peck, Galluci & Schwartz, 1996).

The San Diego Child Care and Development Planning Council Needs Assessment (Bassoff & Shea, 1998) confirmed that families of children with disabilities and special needs report that their children are seldom encouraged to participate in child care, recreation or social programs and are frequently discriminated against when attempting to access those programs. San Diego County, the 7th largest metropolitan area in the United States, was the primary site of this proposed research, where all five sites to be surveyed were found. The number of children from birth to 19 years, the age range examined in this study, is reported to be 811,037 (U.S. Census Bureau, 2000). Of those children an estimated 13,178 children would likely meet the State of California definition of having a “developmental disability.”¹

The Federal Interagency Forum on Child and Family Statistics (1999) reports that approximately 12.3 percent of all (non-institutionalized) children ages five to seventeen have difficulty performing one or more daily activities. That would suggest the number of children in San Diego County who will or may require some type of accommodation in order to successfully participate in group care activities where the ratios of adults to children is anywhere from 1:4 to 1:20 is approximately 99,758.

Examples of the activities in child care, recreation or camp that might require assistance from staff or caregiver adults include difficulty with mobility, self- care,

¹ The Lanterman Developmental Disabilities Services Act, (Welfare and Institutions Code Sec 4512 (a) defines a developmental disability as one that “originates before an individual attains age 18, continues, or can be expected to continue indefinitely, and constitutes a substantial disability for that individual.” The disability must be due to one of the following conditions: (1) mental retardation, (2) cerebral palsy, (3) epilepsy, (4) autism, or (5) a disabling condition closely related to mental retardation or requiring similar treatment but excluding other handicapping conditions that are solely physical in nature.

communication, social emotional development and /or learning. Given the fact that significant numbers of children will experience one or more of these difficulties and recognizing that families are looking for safe, affordable child care and/or after school or summer programs, attention is now being given to the challenges that these families face in accessing appropriate programs. Both a paradigm shift and a willingness to undertake complex change are required if children with disabilities and special needs are going to be able to enter and enjoy after school programs in their communities. The first step in the organizational change that occurs involves a self-assessment and reflection by the organization's stakeholders as to how the organization currently welcomes and/or supports the inclusion of individuals with disabilities.

Resistance to change where organizational culture is imbedded is very common. Lack of awareness, long held stereotypes and biases as well as limited experience with people with disabilities make change even more difficult. Many community organizations believe that people with disabilities are better off in traditional segregated programs and thus do not have to deal with the adaptive work that is required both individually and organizationally to welcome, include, and support people with disabilities. A change in organizational attitudes and culture is required if children with disabilities and other special needs are going to be welcomed and given opportunity for meaningful belonging. In addition, considerable adaptive work is required if these children are going to be able to participate in community children and youth programs in out-of-school hours.

There have been attempts to measure organizational change in relation to increasing diversity and managing diversity initiatives both in industry and in higher education. Judith Katz (1989) suggested that developmental phases are key elements in an

organization's shift toward "multiculturalism" and addressing issues of discrimination and diversity. In an effort to address a lack of diversity on a university campus, Baron and Mitchell (1998), developed a tool called the Organizational Developmental Model of Inclusion (ODMI), which involves a self-assessment on the part of the institution to examine cultural diversity. This researcher adapted the ODMI survey to more specifically address diversity in terms of ability differences. It too was based on the premise that the creation and maintenance of a culturally inclusive institution is a developmental process. The self-assessment tool was called the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI - IWD)*. In order to design, implement and sustain inclusive practices, it is necessary to develop a strategic plan for change. Before that plan can be developed there must be recognition that change is required and identify the external or internal motivators that will facilitate the change. This study measured through a self-assessment questionnaire, the differences in perceptions of four groups of stakeholders as to where the organization is on a developmental continuum of change as it relates to the inclusion of individuals with disabilities.

Context for the Study

A pilot program, designed and implemented in 1995 by this researcher continues to successfully support the inclusion of children with disabilities in a range of children's activities including preschool, summer camps, theater arts, recreation, sports and teen programs and has become a model for inclusive recreation and child care nationally. One of the most critical factors in the success of the model was the impact of an advisory committee made up of stakeholders, defined as parents of children with and without

disabilities, program directors and administrators from the agency as well as interested professionals from outside the agency. The commonality among stakeholders was that they were committed to the inclusion of children with disabilities and they recognized the need to develop a plan to begin the process of inclusion. Another factor in the success of the culture change that occurred was strong and effective leadership which could be described as transformational in nature. The agency's formal leadership as well as a large membership base responded to a challenge to change the way they had been doing business so that they could include these newest consumers and members of the community. The leadership, with recommendation from the advisory committee, re-evaluated their mission statement and became committed to reviewing policies and practices to ensure that they reflected the value and belief that all children have a right to belong. The unofficial response became, "It's the right thing to do." Program directors and parents were given voice and asked to help frame the process and evaluate the outcomes which resulted in broad-based organizational change and a noticeable change in culture.

In the second year of the pilot, members of the Inclusion Advisory Committee with the support of the committee chair and the organization's lead change agent proposed the development of a non-profit organization whose purpose was to continue to support the pilot as well as expand the model to other sites in the county. The vision of this new organization was a belief that all children have a right to belong and that they can and should be welcomed in their neighborhoods and communities in natural environments where they would be if they did not have a disability. In order for that to happen, children and youth community programs would need to embrace a new philosophy,

commit to organizational change and begin the adaptive work necessary to accomplish that change.

Approximately 9 years later, that organization with stakeholder input, strong leadership, and an extensive network of collaborators has provided direct support to the pilot site and thirty-eight additional children's programs representing programming opportunities at more than 147 sites in San Diego County. The organization has also provided indirect support and training to over 6,000 staff from other children and youth organizations across the country that are in the process of, or beginning to explore the concept of including children with disabilities.

Significance of the Study

Results of this study will contribute to the literature in the area of evaluating the *process* of including individuals with disabilities in communities and particularly children with disabilities in child care, recreation and other youth development activities that occur in what is called out-of-school-time. It will support the need for organizations to reflect on whether or not their beliefs, values, and espoused mission statements are congruent with their practices. It will encourage self-reflection by members of the organization as they examine the organization's culture as well as its policies and practices in regard to the inclusion or exclusion of individuals with disabilities. The self-reflection will assist the stakeholders in determining where the organization is rated on a developmental continuum in the *process of inclusion*. Ultimately it can facilitate the organization's effort to establish a strategic plan to support the change and begin to include people with disabilities in meaningful and respectful ways. Finally it should

influence child care policy in the country, specifically school-age care where policy is deficient in terms of addressing the inclusion of children and youths with disabilities.

Research Questions

The following questions guided the research:

- 1) How does each group of stakeholders rate their organization on the developmental continuum of inclusion?
- 2) What, if any, discrepancies exist between the perceptions of the agency's leadership, including the Board of Directors, the Executive Director and the Director of Operations, and the full-time equivalent program staff, based on their rating of the organization on the developmental continuum of inclusion?
- 3) What, if any, discrepancies exist between the perceptions of the parents of children without disabilities, and the parents of children with disabilities, based on their rating of the organization on the developmental continuum of inclusion?
- 4) What, if any, discrepancies exist between the perceptions of the organization, defined as leadership and program staff, and the perceptions of the consumers, defined as parents of children without disabilities and parents of children with disabilities, based on their rating of the organization on the developmental continuum of inclusion?

Proposed Methodology

While there are numerous corporate, as well as not-for-profit, organizations that provide child and youth development programs, for purposes of this study, one model of children's programs, Boys & Girls Clubs in San Diego County, was the source for the research. In this study, lay leadership, management, staff and parents of children with and without disabilities at five specific clubs were surveyed regarding their attitudes and

perceptions of inclusion and their level of participation in the planning and implementation of the organizational changes that supports inclusion. Stakeholders were asked to describe the organizational environment as they re-examined beliefs and values and also ask themselves whether their policies, procedures and practices reflected those beliefs and values. The analysis includes a reference to conditions and characteristics of collaboration, including stakeholder participation as it influences the process. The survey also examined leadership behaviors that were, or were not, occurring as the organization began to learn, adapt and make accommodations for individuals with disabilities.

The insight of the stakeholders reflects on the readiness and capability of the organization to create a sustainable and authentically participatory model of inclusive community. The information will provide a developmental reference for the organization and have direct implications for strategic planning that will improve practices, support staff training, and develop resources. Finally the study will offer recommendations for future practice that will encourage ownership and sustainability of the paradigm.

The *Organizational Developmental Model of Inclusion for Individuals with Disabilities* was administered to at least 25 participants from each of five mid to large size Boys & Girls Clubs in San Diego County that were known to be including children with disabilities. Specific participants were asked to complete the survey and they included individuals from the four categories of stakeholders: leadership; full-time equivalent program staff; parents of children without disabilities and parents of children with disabilities who were co-enrolled in programs within the organizations.

The research study involved a one-time administration of the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI –IWD)*,

(Appendix B). Prior to the data collection the survey was piloted by at least 10 individuals that represented each of the stakeholder groups. Upon evaluating the data and responding to their suggestions, the instrument was modified slightly. The survey instrument and a sampling plan were sent to the Institutional Review Board at the University of San Diego for review and upon approval, the research commenced.

Following a contact with and a formal letter of introduction (Appendix A) to the Executive Director at each of the five Boys & Girls Clubs in San Diego County, an appointment was made to either introduce the surveys in person to the staff and leadership of the organizations, or to deliver the surveys to the organization with cover letters, consent forms (Appendix D) and self-addressed stamped envelopes. The parents of typically developing children or children without disabilities, as well as the parents of children with disabilities were identified by program directors at each site, and the surveys, consent forms (Appendix E) and self-addressed stamped envelopes were distributed to them. The hard copy surveys were returned by mail or picked up from the clubs in sealed envelopes in a mail box in the Program Director's office.

Data Analysis

After surveys were completed and returned, the raw data was entered into SPSS 13.0 by group and organizations. To address the first research question, the mean scores for each of the five categories of the survey tool were computed and standard deviations for the five sectional scores and the overall score was presented for the organizations as well as for the four groups surveyed within the organizations.

To answer research question two, independent sample t-tests were used to statistically test for differences between the responses of the leadership and the staff. Similarly,

question three statistically compared the responses between parents of children without disabilities and parents of children with disabilities. The fourth research question identified the discrepancies between the responses of the *organization*, defined as leadership and staff, and the *consumers*, defined as parents of children without disabilities and parents of children with disabilities. For all three research questions, the $p = .05$ level of confidence was used in the statistical tests.

By utilizing the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI – IWD)*, the survey results can provide a point of reference to initiate or continue the process of organizational change that is required for the institution to move toward being inclusive for individuals with disabilities.

Assumptions

The assumptions of the researcher were that there would be, in fact, some discrepancies between the groups of stakeholders, particularly between the perceptions of the families of children with disabilities and the leadership of the organization. It is assumed that many times an organization's leadership will perceive that because there are now children with disabilities participating in some programs and services, that they are further along a developmental continuum of inclusion, while in fact they may be at a level of symbolic inclusion or supported inclusion. Because this is a new way of doing business and they are now including a new group of consumers, the perception is likely that they are finally an inclusive organization whose practices are congruent with organizational beliefs and values. Families of children with disabilities and even program staff are likely more aware of the extent to which the organization has embraced

the inclusion of individuals with disabilities and whether or not they have provided the necessary supports to make the experience meaningful.

Limitations of the Study Design and Methodology

There were a number of limitations in the proposed study. The study was conducted in only one example of children's programs among a system of many different organizations that provide "out-of-school-time" programs and activities. The study was limited in that it only surveyed participants and organizations in one distinct geographic and cultural environment, that of Southern California, specifically San Diego County. The data collected was also limited to self assessment based on limited experience and knowledge of the organization's history and culture. In addition, there may have been some respondents who would have been more comfortable completing the questionnaire in their first language, rather than in English. There are some inherent limitations that exist when utilizing a questionnaire to provide evidence, although Babbi (1990) and Zikmond (1991) remind us that similar limitations also inhibit the validation of any study or research project, regardless of the method. Because the study is quantitative in nature it lacks the ability to collect much richer data that might better project the feelings of families whose children have probably experienced discrimination or rejection. In addition, the study did not examine the feelings of the providers who might have positive or negative experiences that have influenced biases and stereotypes regarding individuals with disabilities.

Definition of Terms

For purposes of this study, "children with disabilities and special needs" will refer to those children between the ages of birth to eighteen years who are:

- 1) Protected by the Americans with Disabilities Act (ADA)
- 2) Eligible for special education services under the Individuals with Disabilities Education Act (IDEA)
- 3) At risk of a developmental disability as defined by the Early Intervention Services Act, or
- 4) Who do not have a diagnosis but whose behavior, development, and /or health affect their families' ability to find and maintain child care services.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

This chapter provides an overview of the literature focusing on four major themes related to the proposed research. The first is the history of disability, including the formation of cultural values, the impact of civil rights legislation and quality of life issues that highlight the move to community integration, empowerment of parents, self-determination and striving for interdependence. The second theme identifies lessons learned from regular and special education, the only system that has extensive documentation on the history of including children with disabilities in natural environments. The significance of collaboration, partnerships, and authentic participation of stakeholders in building and sustaining high quality inclusive practices will be described as will the need for providing necessary supports. This section will address barriers to inclusive education and describe strategies for successful inclusion. The third area reviews organizational change as it relates to organizational culture, the influence of stakeholders in facilitating change and will examine one specific area of organizational change, that is, diversity initiatives. The final theme will address the role of leadership in organizational change that is required of communities that are ethically and morally committed to improving the quality of life for people with disabilities. The examination of leadership will address concepts of empowerment, shared decision making, intra-organizational and inter-organizational collaboration, boundary crossing, and capacity building within organizations and communities that signal a systems wide change that fosters respect for differences and movement toward human interdependence.

Historical Perspective of Disability

Influence of Cultural Values

History has recorded substantial shifts in the perception about individuals with disabilities. Hewett and Forness (1977) suggested that cultural values associated with disabilities have been influenced by the conditions under which humans have lived. They described four major determinants of those social conditions.

First, they discussed the *Threat to Survival* determinant that related to primitive times when skills such as speed, agility, cleverness and strength were necessary for survival. There was little use for those who could not contribute to the good of the group and the practice of eugenics, i.e., eliminating individuals who were considered burdensome, was common during Greek and Roman periods. The Romans practiced infanticide of children who were female or deemed defective. It is possible in today's society to hear references to these survival determinants when citizens or policy makers debate the cost of medical care or education provided for those with disabilities using the justification that it takes away from the seemingly more capable in our society.

The second condition described by Hewett and Forness was *Superstition* which related to unexplained appearance and behaviors of individuals with disabilities. Early Greeks, Chinese, Egyptian, and Hebrew cultures attributed disabilities to intervention by demons. They used exorcisms, magic potions and ritualistic ceremonies that ranged from passive to punitive and tortuous, including flogging and burning people at the stake. It was not uncommon in those times for parents to turn to priests or clergy for divine intervention or they might abandon children with disabilities in monasteries. There was also superstition and fear that heterosexual contact between persons with disabilities would lead to

perpetuation of disabilities. To prevent this, mental health facilities segregated clients by gender, deterring all social contact and sterilization was advocated by many. A final superstition was an association that cognitive deficiency leads to violent or deviant behaviors, which has resulted in resistance over the years to the formation of group homes for persons with disabilities.

The third determinant *Service* was a means to counter the *Threat to Survival*. There have been throughout history, advocates for the humane and benevolent treatment of individuals with disabilities. Plato, while he advocated for removing children who were defective from society, also encouraged families to serve their disabled members. As reported in Coleman (1972), "If anyone is insane...let the relatives of such a person watch over him in the best manner they know of and if they are negligent, let them pay a fine." (p.28). The Christian influence in the Middle Ages provided comfort to individuals with disabilities while European, Asian, and Middle Eastern societies began to train people with sensory impairments. Mental health facilities were established as early as the 1500's and are recorded in American history in the 17th century. By the 19th century there was a move for more humane treatment facilities that were devoid of physical abuse and restraint. At the same time the French were introducing agrarian work colonies for individuals with disabilities. Sigmund Freud, B.F. Skinner, Edourd Seguin and Alfred Binet were advocating for educational and rehabilitative services for individuals with disabilities. Their influence was partially responsible for the philosophy of custodial care, educational services and direct therapeutic intervention. This model of service for individuals with disabilities has evolved from segregated services to a wide range of services for people with disabilities from birth to death.

Finally, the fourth major determinant associated with disabilities, *Science*, opposed superstition and relied on natural and objective study of individuals with disabilities. The scientific movement can be divided into periods of pseudoscience and empirical science. Evidence from the Stone Age suggests that cavemen practiced a form of brain psychosurgery to remove evil spirits. The Greeks and Romans devised diet treatments, hydrotherapy, and sunshine treatment for studying cognitive deficits. A final example of pseudoscience was the practice of bloodletting and partial drowning during the 17th and 18th century to rid the body of mental illness. The greatest contribution of science in the 19th century was Itard's treatment of the feral child, Victor, which introduced case study techniques to modern day scholars as he monitored educational interventions and behavioral outcomes. The 20th century witnessed dramatic advances in both measurement and treatment of persons with learning and behavior problems.

This historical reflection on *survival, superstition, service and science* clearly helps us appreciate our current understanding of individuals with disabilities. While *service* and *science* are the accepted trends, parents and practitioners must continue to advocate for treatment reflecting those trends. This study supports why it is so important to facilitate cultural change as it relates to society's perceptions about people with disabilities.

Influence of Disability Rights

On December 15, 1791, the Bill of Rights became part of the United States Constitution. Article Five of the Constitution declared that "no person shall be ...deprived of life, liberty, or property without due process of law." After the Civil War, Article Fourteen was added to the Constitution. That amendment stated that "no state shall make or enforce any law which shall abridge the privileges or immunities of

citizens.” It also added that no state could “deny to any person within its jurisdiction the equal protection of the laws.” These articles of the Constitution mean that people cannot be treated differently solely because of disabilities.

The Constitution as well as various federal and state laws clearly state that all citizens are due fair and equal treatment. It does not mean that all people have equal ability but that all citizens are due the same opportunity to use their ability, knowledge, and property. The rights that are universally guaranteed by the United States Constitution to each citizen regardless of disability include (a) Access to the courts and legal representation, (b) Free association, (c) Right to contract, own, and dispose of property, (d) Equal educational opportunity, (e) Equal protection and due process, (f) Fair and equal treatment by public agencies, (g) Freedom from cruel and unusual punishment, (h) Freedom of religion, (i) Freedom of speech and expression, (j) Right to marry, procreate, and raise children, (k) Privacy, (l) Services in the least restrictive environment, and (m) Right to vote. In addition to rights guaranteed by the Constitution, federal and state laws also protect the rights of people. Five major laws in the past four decades have particular application to people with disabilities and they are briefly described in this literature review according to the decade in which they became law.

Legislation in the 1960s

The 20th century witnessed slow but steady progress in providing services for people with developmental delay and mental retardation. In 1960, with the election of John F. Kennedy as the 35th President of the United State, a new period of humanitarianism unfolded for the disabled and the disadvantaged. In an effort to improve the quality of life for people with mental retardation and mental illness, the President appointed a

special President's Panel on Mental Retardation in October, 1961, charging them to conduct an intensive search for solutions to the problems of the mentally retarded and correct the failures.

The panel visited international programs, did extensive research and finally submitted to President Kennedy a report with 112 recommendations. Within a year Congress passed far reaching legislation supporting the President's intent including PL 88-156, the Maternal and Child Health and Mental Retardation Planning Amendments of 1963, and PL 88-164, the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1962. Over the next 20 years, Congress passed an additional 116 acts or amendments intended to provide support to persons with mental retardation and their families in the areas of health, housing, employment, education, income maintenance, civil rights, and social services including Social Security benefits, nutrition, transportation and vocational rehabilitation. While the services were needed, the rate at which programs were created produced an undesirable situation with eleven different federal agencies and over 135 different funding programs, all with different eligibility requirements. Despite the chaos and complexity of the system, thousands of persons with mental retardation in the sixties and early seventies benefited from new or expanded programs with the states contributing resources.

One of the outcomes of the President's Panel was to develop an array of community-based services from birth to death for persons with mental retardation. The panel recommended that states examine their own needs and, in partnership with public and private agencies, address those needs. The result was a series of overwhelming challenges to develop fiscal and resource services to persons with mental retardation and

their families, who were grossly underserved in most states. Neither the country nor individual states were prepared to undertake the broad social commitment that was required to adequately serve persons who qualified for the recommended services. What did occur, however, was a sensitization to the challenge of comprehensively serving persons with mental retardation, thus a paradigm shift occurred. In the future, policy makers realized that federal participation, comprehensive planning and participatory techniques by the stakeholders would be required.

Legislation in the 1970s

Four acts seemed to have the greatest impact for supports and services for people with disabilities in the 1970s. In 1970, The Developmental Disabilities Services and Facilities Construction Act (PL 91-517), became law. This Congressional act was intended to assist states to assure that people with developmental disabilities received the care, treatment, and other services necessary to enable them to achieve their maximum potential. This would be accomplished through a system that coordinates, monitors, plans, and evaluates services and ensured the protection of the legal and human rights of people with developmental disabilities.

Over the years the Act significantly impacted programs for people with developmental disabilities, although there was administrative resistance from several subsequent presidents. The initial Developmental Disabilities Act (P.L. 91-517) defined developmental disability “as a disability attributable to mental retardation, cerebral palsy, epilepsy, or other neurologically handicapping condition found to be related to mental retardation or requiring treatment similar to that for mentally retarded individuals”. One of the most important outcomes of the Act was the requirement that state Councils

include representatives who were consumers along with representatives from principle state agencies, local agencies and non-governmental organizations and groups concerned with services for persons with developmental disabilities. The Councils, while never adequately funded, did develop small demonstration and technical assistance projects and most importantly, were given the authority to assure adequate advocacy services. This was the beginning of a system that would be responsible for advocacy and protection of individual rights of persons with developmental disabilities.

Three years later in 1973, The Rehabilitation Act (PL 93-112), a law often described as the first civil rights act for persons with disabilities was passed. The law prohibited discrimination on the basis of disability and required employers and educational programs to make reasonable accommodations to meet the needs of persons with disabilities.

Later in 1975, The Education for All Handicapped Children Act (PL 94-142), re-titled in 1990, the Individuals with Disabilities Education Act or IDEA, required that all children with disabilities be provided a free and appropriate public education and that they be educated in the least restrictive environment. It also provided for due process provisions and placed a heavy reliance on parental consent to the Individualized Education Program (IEP) that must be designed for each child. The law was amended in 1983 to include children from birth to age 3 (at each state's discretion) and in 1986 was expanded (PL 99-457) to provide grants to states for the development of coordinated interagency systems to provide early intervention programs. In 1990, under another amendment (PL 101-476), the law was reauthorized and further expanded. The name of the law was changed to the Individuals with Disabilities Education Act (IDEA),

reflecting the concept of “person first” language. Early intervention services under PL 99-457 were strengthened and opportunities for infants and toddlers with disabilities were expanded to include transportation, assistive devices and technology services. IDEA requires, as part of an IEP, that each student be provided with transition services which are intended to promote the individual’s movement from school to post-school programs, including postsecondary education, vocational training, supported employment, continuing education, employment and community living.

Another key legislative act that greatly impacted supports and services for people with disabilities was The Developmental Disabilities Assistance and Bill of Rights Act of 1975 (PL 94 -103). The bill authored federal financial support for planning, coordinating, and delivering specialized services to people with developmental disabilities (as defined in PL 94 -142), and the law has continued to be extended through amendments in 1984, 1987, and 1990. The Act provides continued federal support for State Planning Councils on Developmental Disabilities, State Protection and Advocacy (P & A) systems, and University - Affiliated programs (UAPs).

Legislation in the 1990s

There was one very significant piece of legislation during the 1990s, The Americans with Disabilities Act (PL101-336), which is often referred to as the broadest piece of civil rights legislation ever for individuals with disabilities. The ADA protects them from discrimination in employment, transportation, public accommodations, telecommunications, and activities of state and local governments. It offers the same protections that are extended to other groups on the basis of race, sex, national origin, age, and religion.

These laws reflect in the last several decades an emerging recognition that it was time to affirm the rights of individuals with disabilities. It also occurred at the same time as the first perceptible paradigm shift in America in terms of the way persons with disabilities were viewed, from being seen as intrinsically inferior to having the same civil rights as all Americans. An outcome of the legislative mandates was a move toward community integration of people with disabilities. A description of ways that integration occurred is outlined in the next section of the literature review.

Quality of Life Issues for People with Disabilities

Community Integration

Taylor, Biklen and Knoll (1987) described the principles of community integration that began to address the issue of quality of life for people with developmental disabilities. These principles included the fact that all people with developmental disabilities belong in the community and should be integrated into typical neighborhoods, work environments, and community settings. The principle suggests that physical placement, while necessary, is not a sufficient condition for community inclusion. Supports should be given to people with developmental disabilities in families and typical homes in the community and there should be efforts to encourage the development of relationships between people with developmental disabilities and other people, relationships that are characterized by reciprocity and mutuality. Finally, people with developmental disabilities should be given opportunities to learn, with an emphasis on practical skills and consumers and parents should be involved in the design, operation, and monitoring of services.

This reference to parents and consumers being involved in the design, implementation and monitoring of services supports the premise for this research study. It is critical that as systems begin to change and the culture in organizations change to reflect diverse populations, that parents of children with disabilities and/or the person with a disability be involved in design, implementation, and evaluation of services.

The Empowerment of Parents

Much has been written in social psychology about the roles parents play in children's lives and recently, there has been considerable attention in the literature about parents of children with disabilities who are presented with special challenges in terms of their need to be advocates. Darling (1988) describes the role assumed by many parents of children with disabilities as parental entrepreneurs (p.141). The defining behaviors of the parental entrepreneur include seeking information, seeking control, and challenging authority in order to secure services to meet the needs of the disabled child. Rather than passive acceptance of the child's condition, the parental entrepreneur role involves action to bring about social and service arrangements that the parents envision being in the child's best interest. For a number of parents, inclusion in their communities and in natural environments is one of those choices. Many parents, however, are less skilled at or comfortable with advocacy and they often defer to the professional's opinions and recommendations. These parents can be invited into the participatory process by the organizations in the community who wish to be inclusive to all children.

Another outcome of the process that is involved in creating inclusive communities is the impact on the children without disabilities who share community experiences. One outcome is empathy and a genuine respect for differences. The result is an appreciation

that as community, we are all interdependent on one another. It is important to involve parents of children without disabilities or typically developing children themselves, to have voice in the process of creating and sustaining inclusive communities.

Self Determination

One of the tragedies of the current systems approach to providing supports for people with developmental disabilities is the impoverishment of those individuals within a system that spends billions of dollars annually. The system, which they did not design, seems to contribute to the continued isolation of people with developmental disabilities from their communities and an overwhelming lack of friendships and relationships in their lives. The concept of self-determination asks policy makers to examine the disparities between the dreams of individuals with disabilities and the expenditures made on their behalf by other individuals. They describe a desire to direct cash or disposable income to help to navigate the community and provide the supports they need to choose where, and with whom, they would like to live, how they would like to be employed, and to determine how they can become connected to their communities based on their interests. The concept called *person-centered planning* enables individuals to exert some control over those choices, hopefully allowing more freedom and opportunities for community relationships and reciprocity, which is central to any notion of friendship and belonging.

Concept of Interdependence

Interdependence is a term that implies interconnectedness or interrelationship between two entities, yet most references to interdependence in the literature are geopolitical. Al Condeluci (1995), while preparing his book, Interdependence: The Route to Community

found only a few references to human endeavors. They included Martin Luther King, Ghandi, and several others who suggested that “Our futures are interrelated, that none of us are free if any of us are vulnerable and that interdependence is a natural course for protection” (p.60).

Stephen Covey (1989) wrote about human interdependence as a maturity continuum and describes dependence as the paradigm of you, independence as the paradigm of I, and interdependence as the paradigm of we. He discourages independent thinking and acting that may serve individual needs but does not add to teamwork and suggests that interdependence is necessary to succeed in organizational life, in marriage, and in family. Covey summarizes his view in a manner that can be used to reflect on the medically oriented rehabilitation model that has been the foundation for human services:

Interdependence is a choice only independent people can make. Dependent people cannot choose to be become interdependent. They don't have the character to do it; they don't own enough of themselves... As you become truly independent, you have the foundation for effective interdependence. (p. 60).

Covey's analysis reminds us that there is more to life than independence, which is often the primary goal of rehabilitation and yet the danger of being able to take care of oneself and become autonomous often results in disconnection from others. Condeluci (1995) contrasts his concept of interdependence from the medical model and suggests that it focuses on capacities, not deficits; it stresses relationships, not congregations; it is driven by the consumer, not the expert; and it promotes micro/macro system changes rather than fixes.

Condeluci's recognition that the challenge is the same suggests a radically different approach to viewing disability in society, one that requires actions. The interdependence paradigm defines the problem of disability as not what is wrong with the person, but as a deficit in the system that does not provide appropriate supports that encourages and allows full participation for all. The greatest barrier is attitudinal and those attitudes intensify the devaluation and dependencies experienced by people with disabilities who have become distanced from the communities in which they live. Condeluci describes actions that are necessary to move along the maturity continuum that lead to interdependence.

One action necessary to support the interdependence paradigm is to pay attention to capacities and passions. Mount and Zwernik (1987) in describing the concept of *Futures Planning*, caution us to avoid the medical model approach in which the expert defines strengths and needs. They recommend that support people list out all the capacities common to the focal person, which might include not just strengths but interests, preferences, attributes, gifts and passions.

The most important dimension of interdependence is found in relationships. Marsha Forest (1988) was one of the first to remind us that most of the relationships in the lives of people with disabilities are the caregivers and experts who are paid to be with them. Knowing how important relationships are for people with disabilities and their families, she advocated that public schools in North America embrace a social networking technique by fully including children with disabilities in regular education classrooms and facilitating opportunities to develop natural friendships. Clearly there must also be

opportunities for developing friendships in out-of-school hours, including child care and recreation.

Another major action required in the interdependent paradigm is to acknowledge and develop supports that will help people with disabilities enjoy life. The medical model characterized by repetitive evaluation and task analysis often encourages teaching and repetition of tasks that have little meaning. While skill building surely has a place in improving confidence and competence, it often has little to do with real life (Gold, 1980). Surely social skill development and finding ways to connect in the community are more important than spending countless hours doing meaningless tasks that some expert has determined is necessary.

Finally, we must recognize that the expert paradigm has created systems that have promoted a culture of laws and customs that have disenfranchised people with disabilities. The best action to date to remedy that injustice was in 1990 with the passage of the Americans with Disabilities Act (ADA), (PL 101-336), which was the first real effort to support the interdependence paradigm. Medicaid reform and attendant service legislation are a major necessity if community participation is to become a reality for people with disabilities. Consumer control and advocacy must continue to drive those efforts. The issue of advocacy cannot be addressed without attention to the movement to encourage people with disabilities to advocate for themselves, a movement that has gained momentum over the last decade.

Lessons Learned from Education

General School Reform

Federal, state and local leaders have been engaged in school reform efforts since 1983, when *A Nation at Risk* compiled by the National Commission on Excellence in Education, reported that our public schools were not adequately preparing American children and youth for changing times (Smith, 1997). Sashkin & Egermeier (1993) suggest that most school improvement strategies have been criticized for being “fix-it” models, as in fix the people, fix the parts, fix the schools and now, fix the system.

American citizens, institutions and policy makers continue to call for educational reform. Advocates for school reform, while recognizing the many challenging issues that face students and educators, caution that focusing on one isolated need or targeting one group of students is inadequate. Despite the principles first addressed in *Brown v Board of Education* (1954) that maintained separate was not equal, too many schools continue to reflect separation of students in terms of race, class, ability and primary language. Effective schools meet the needs of a diverse group of students including students at all points on the learning spectrum, second language learners, socio-economically disadvantaged students and students with disabilities.

One particular area of educational reform that draws much attention and continues to be strongly debated is the move to include children with disabilities in regular education classes in their neighborhood schools. Inclusive classrooms are thought to better prepare all students, those with and without disabilities, for the challenges of living together in society (National Association of State Boards of Education, 1992). Raison, Hanson, Hall and Reynolds (1995), Van Dyke, Stallings and Colley (1995), and Yatvin (1995), suggest

that one of the reasons that the issue of inclusion is so divisive and emotionally laden is that perceptions linger from our own direct experiences in school settings. Most of those experiences were limited and probably reflect a lack of knowledge about people with disabilities. There is additional resistance to inclusion given the fact that the culture of special education has developed segregated and isolated systems with separate sets of beliefs, rituals and symbols (Skrtic, 1991). The system marginalized students that they considered unsuccessful and encouraged that education be offered in different or “special” environments.

Barriers to Creating an Inclusive School

Thousand and Villa (1995), described what makes schools so intractable and resistant to reform. They cited inadequate teacher preparation, inappropriate organizational structures, policies and procedures, lack of attention to the cultural aspects of schooling, and poor leadership.

They suggest that the first barrier to school reform is the categorical lack of curricular focus on collaborative skills and ethics in teacher preparation. In a national survey on teacher preparedness, Lyon, Vaassen, and Toomey (1989) found that 80% of teacher respondents indicated their teacher preparation programs left them inadequately prepared to meet differing student needs. Universities are preparing teacher candidates to expect diversity in the classroom and develop the skills to respond to different student learning styles, rates and needs. Yet many continue to sort their teacher candidates into categorical programs such as special education, general education, gifted and talented, and English as a Second Language, which may limit their ability to work with children with very diverse learning abilities.

Other educators have described what they consider another reason for intractability of schools as organizational structures, policies, and procedures. Deal (1987), describes schools as compartmentalized organizations that thwart rather than support collaboration and coordination of services and resources. Most schools continue to track students by ability level and have formally created a separation between general education and special education with special education being a freestanding system (Wang, Reynolds, & Walberg, 1988).

Resistance to the familiar *culture* of school is the third reason suggested for the failure of school reform. Culture is often defined as the "historically rooted socially transmitted set of deep patterns of thinking and ways of acting that give meaning to human experiences" (Deal & Peterson, 1990, p.8). All organizations and institutions have a culture, a starting point, a history defined by philosophy and mission and generally driven by values, norms and practices. That culture provides implicit messages, messages often sent by management that tell the organization what the organization's values are. Smith (1993) states, "During normal times, a leader's job is to perpetuate the culture" (p. 17). However Sue and Sue (1990) remind us that culture is fluid and can evolve with changing goals. Members of organizations are challenged to bridge the gap between changing priorities or goals to influence practices and systems change. A move from a fragmented to an inclusive school culture requires change agents that will celebrate diversity as they develop new rituals, traditions, symbols and new heroes.

The fourth reason cited in the literature for school's intractability and resistance to innovation is the naiveté and/or cowardice of change agents (Sarason, 1990). Many school leaders are naïve in that they fail to recognize the complexity of systems change

and they often fail to link various change initiatives together such as multi-aged grouping, thematic and interdisciplinary curriculum, multicultural education and inclusive education. The weakness of change agents is evident when they refuse to deal with conflict and emotional turmoil. Many leave their positions of leadership rather than commit to the projected time frame for true organizational transformation to occur.

The same issues that are described as barriers to inclusive education exist in organizations that are expected to include children with disabilities in out-of-school time programs. Many youth service organizations with long histories of supporting children and proposing to enrich children's and family's lives appear resistant to inclusion. The reasons for the intractability and resistance are the same reasons as above including inadequate staff preparation, cultures that are imbedded and resistant to change, inappropriate organizational structures, policies and procedures and poor leadership. The rationale for this study is to examine the perceptions of the membership and staff within the organizations as to the congruency between their beliefs and their practices. The intended outcome will be to encourage a collaborative approach between consumers and the organizations to examine policies and procedures, determine strategies for facilitating change and providing accommodations and adaptations as needed.

Inclusive Education

The move for inclusive education has its roots in the principle of normalization, a concept first described by the Nordic countries and later developed in the United States (Wolfensberger, 1972). More than twenty-five years after the passage of P.L. 94-142, the Education for All Handicapped Children Act (EHA), now called the Individuals with Disabilities Education Act (IDEA), debate and litigation continues regarding the

provision for Least Restrictive Environment (LRE). In describing why Congress felt that integration was imperative, Gilhool (1989), reminds us why it is not recommended to segregate students with disabilities: (1) all children learn from modeling the behavior of other children, (2) children must attend school together if students with disabilities are to lead a decent life in the community as adults, and (3) parental and community supervision of schools would ensure equitable resource distribution and greater protection of all students, if children with disabilities were educated with their typical peers.

Inclusive education evolved as a viable option for parents of children with disabilities in the 1990s and while it has been moderately successful in some districts and states, it is generally very slow to be embraced by the majority of schools in this country. There seems to be promise in aligning current systemic reforms in education with the reauthorization of IDEA and with that promise, the opportunity for equity and excellence in American education could be a reality for all of America's children and youth.

Sashkin and Egermeier (1993), suggest that three perspectives have dominated the nature of educational change in America. The first perspective is that educational change is created by innovation and strategic planning. The second is that change in education is brought about by legislation and policy directives imposed by parties outside the school system, generally in a top-down approach. The third perspective is that educational change is created from the bottom up in a system that encourages value changes within organizations. Most current reform efforts combine these perspectives and suggest that the best approach to change education is to combine top-down and bottom-up strategies through coordinated state policies that support changes at the local level.

Top down administrative support is necessary to create the systems change for inclusive education. Ayres, Meyer, Erevelles and Park Lee (1994) in their work identifying support variables needed to create the change necessary for inclusive education state the one variable generally lacking is leadership. Other studies also stress that leadership is the key to system change during the philosophy building and planning process (Staub, et al., 1996).

At the same time change and support from the bottom up promotes inclusive school environments. Inclusion is not a product, but a process. To do it and do it well requires commitment, collaboration and leadership. Discovering our commonalties, minimizing differences and creating opportunities to care, lead to truly inclusive and caring communities and clearly change people's attitudes. We know that as children without disabilities experience increased interaction with children with disabilities in integrated and/or inclusive classrooms, they have very different attitudes than previous generations and do not tend to stereotype people. Many authors believe that by capturing the attention of children at an early age and exposing them to enriching experiences with people who have disabilities, favorable beliefs will be established and remain for a lifetime (Morrison & Ursprung, 1987).

Collaboration in Inclusive Education

This section of the literature review summarizes the ingredients of successful inclusion as documented in the literature. A number of studies including Baron and Mitchell (1998) remind us that meaningful change cannot occur without institutional commitment after a period of self-reflection of attitudes, beliefs and values. That commitment involves defining a vision that supports the organization's mission statement

and like other scholars, they suggest that voices of diverse stakeholders are part of the process. Recognizing that change is inherent in bringing together people with diverse perspectives and experiences, a process to measure that change is necessary, which suggests strategic planning, followed by implementation and evaluation.

One ingredient that has been consistently mentioned in the literature as necessary for supporting inclusive education is effective collaboration. Falvey (1995), in describing the strategies necessary for effective collaboration, considers collaborative teaming as the heart of the inclusion process and recommends a specific style of interaction and strategic planning that involves shared decision making and ownership. Friend and Cook (1992) further describe the characteristics of effective collaboration, including the following: voluntary participation, parity among participants, mutual goals, shared responsibility for participation and decision making, shared resources, and shared accountability. They remind us that one of roles of the collaborative team is to become a "learning team" that continually identifies barriers and facilitators while ensuring that family members are included as decision makers rather than passive recipients.

Many references in the literature reiterate the need for all stakeholders to be involved in planning and implementation of inclusive practices if true systems change is going to occur. The references consistently include parental involvement as an essential component of effective inclusive schooling, positive outcomes for students with disabilities and opportunities for acceptance, interactions, and friendships in inclusive settings and the need for collaboration among school personnel.

The literature reminds us that inclusion is a process, not a product and that it takes time and energy. It requires creating a shared vision, examining assumptions and values,

utilizing a common language, building trust, holding regular meetings and agreeing to a process of self-evaluation. The United States is in the process of a paradigm shift. Finn (1990) suggests that during paradigm shifts, “conflicting world views can exist side-by-side for many years, perhaps for generations” (p. 586). While this study will recommend strategies for creating inclusive communities through the use of a self assessment tool, there is a need to identify barriers to inclusion that impact the process.

Organizational Change

This section of the literature review highlights research about organizational change with an emphasis on the process of culture change. The emphasis on culture change provides a context for examining the climate of an organization regarding inclusive practices. This researcher contends that before an organization can design, implement and evaluate change, it must assess its current culture, address biases and stereotypes and begin to determine if their practices are congruent with their espoused values.

Diversity Management

Managing diversity is a high priority issue for most contemporary institutions (Cox, 1993). It requires a shift in thinking and a strategic plan to implement. The benefits of increasing organizational diversity have been well documented (Copeland, 1988). When managed properly, diverse groups and organizations have performance advantages over homogenous ones. They also suggest that while there is often interpersonal conflict and turnover, leadership is critical to move organizations toward a transformation to multicultural institutions. Part of the leadership’s responsibility is to champion the cause for diversity, role-model the behaviors required for change, articulate and confirm the group values and assist with the work of moving the organizational forward. Heifitz

(1994) would describe this process as adaptive work which “consists of the learning required to address conflicts in the values people hold or to diminish the gap between the values people stand for and the reality they face (p. 23)”.

There are positive outcomes from a strategic diversity initiative. Cox (1993) reported employees that experience a sense of being valued are more conscientious and innovative and conversely, stereotyping and prejudice cause members of minority groups to feel less valued and less apt to be as invested in the organization. In addition to economic performance improvements, two other goals are facilitated by managing diversity, legal obligations and more importantly, moral, ethical and social responsibility goals (Cox, 1993). Arredondo (1996) suggests when organizations develop a humanistic culture; they convey a message of value. Others concur that attention to the “people factor” must be central and key to the success of any diversity initiative (Cox, 1993; DePree, 1992; Smith, 1993; and Walton, 1990).

Nearly twenty years ago the "diversity model" was introduced, as a concept in response to changing needs in the American workplace. The model, according to scholars, was intended as an intervention and a proactive approach to fully and equitably utilize, integrate and reward workers of different racial/ethnic and gender backgrounds (Cox, 1993). The model supports the philosophy that diversity is a desirable goal in itself and recognizes that this approach demonstrates more than simple acceptance of diversity but truly values diversity. The model in employment, as well as education and not-for-profit organizations, has primarily addressed diversity as a race, ethnic and gender issue and almost nowhere has there been reference to ability differences in diversity initiatives.

The model, as it has existed, recommends diversity initiatives that address increasing sensitivity to cultural differences, developing the ability to recognize, accept and value diversity; minimizing patterns of inequality experienced by women and minorities, improving cross-cultural interactions and interpersonal relationships among different gender and ethnic groups, and modifying organizational culture and leadership practices (Carrell & Mann, 1995, Cox 1993; Loden & Rosener, 1991). Whether or not organizations achieve this goal of managing workplace diversity depends in large part on an organization's diversity climate (Cox 1993). He contends that the climate, which is determined by a variety of organizational factors as well as individual and group factors, influences employees' receptivity to diversity and diversity-management initiatives by the employer.

Based on the importance of the organization's diversity climate, researchers have begun to identify and document the key factors in organizations that enhance or harm diversity-management efforts. Adler (1991) examined whether the receptivity or readiness of organizational members to support diversity depended on their perceptions as to whether the outcomes would be positive or negative. She suggested that, until very recently, cultural differences in organizations were viewed as negative, invisible or illegitimate. In true multicultural organizations, effective diversity management is not viewed as a win/lose situation but rather as one offering mutual benefit.

The importance of interpersonal relationships in the workplace is considered central to the experience of members of different racial and gender groups. (Soni, 2000). Interpersonal relationships involve interpersonal trust, managing uncertainty and anxiety, minimizing misunderstandings, and creating inclusive messages (Gudykunst, 1994).

Tierney (1992) in his writings reminds us that rather than suppressing differences we should honor them and build a commonality between us. He states, "We are often told to build community in our institutions, but we are left with a feeling that we neither have the fiscal nor moral tools to do so" (p.16). The practice of welcoming and embracing people with disabilities into our organizations reminds us of the opportunity we have to build community, and to honor and celebrate differences.

Arredondo (1996) contends that to promote the concept and practice of diversity management is to support a new paradigm for present and future change, based on cultural relativity, open-mindedness, reciprocity and continuous learning. She reminds us that diversity is not new. Despite the assimilation-only approach that was advocated by our country's early politicians and educators, many different models of acculturation, integration and segregation have occurred in the last two centuries. A goal of diversity management is to promote organizational culture change. Arredondo suggests that it occurs through a deliberate, strategic diversity initiative, i.e., a developmental model designed to promote the process of this paradigm change.

The premises and practices of diversity management include people as its focal point and remind organizational leaders to have a clear understanding of the avenues that must be created to communicate the possibilities in a convincing and proactive way. The core of Arredondo's (1996) theory is that diversity management is the key to promoting dignity and respect in the workplace and it positions people as a necessary factor in organizational success. Because diversity management is a strategic organizational goal, it requires a shift in thinking with a focus on personal and organizational culture; cultural differences, culture change, and cross-cultural relationships based on interdisciplinary

knowledge. Diversity management requires approaching people as individuals rather than categories or under-represented minorities. The ability to take risks is considered an asset in diversity management and most importantly the process requires visionary leadership and empowered relationships.

Change as a Process

Webster (1973) defines change as “to cause to be different; alter or to lay aside, abandon or leave for another” (p. 224). Numerous authors have addressed the planned change process, including Lippett, Watson and Wesley (1958), which was perhaps the most ambitious effort to address change at the individual, group, organizational, and community levels. Cox (1974), Sower, Holland, Tredke & Freeman (1957) and Warren (1978) wrote about purposive community change and Kettner, Daley and Nichols (1985) have addressed professionally assisted organizational and community change efforts.

Many early efforts at organizational change were characterized by a concentration on "processes" rather than "outcomes" (Odiorne, 1967). Schaffer and Thomson (1992) argued that to focus on results during a change program might provide benefits that might be lost with an overemphasis on process. Nadler (1981) recognized that whether the attempt to change is guided by internal or external factors or is modeled after a specific change method, it is problematic. He described the need to motivate people to change and recommended the organization establish a means to manage the transition and shape the political aspects of the change process. He cautioned about the outcomes including overt resistance to change, particularly if the participants feel a lack of influence or

control because of not being involved in the early aspects of problem solving and only experiencing the intended change when implementation begins.

Connor (1993) and Beckhard and Harris (1987) described a model that reflected change as a process, a process that includes a present state, a transition state and a desired state. Tichy and Devanna (1986) also supported a theory of change as a process of transitions from ending of a past, changing directions and followed by a new beginning. Tichy and Ulrich (1984) suggested four specific stages in organizational transformation describing management activities that are necessary to support the organizational revitalization. The stages they described include: feeling a need to change, based on their ability to scan the environment; identifying and responding to stakeholders; creating a vision that is congruent with the leadership philosophy and style; mobilizing support and a commitment through dialogue; modeling desired behaviors and attitudes. The final stage is institutionalizing by transforming the vision into reality, their mission into actions and their philosophies into practice. This last stage requires tremendous leadership that at a deeper level shapes and reinforces a new culture that fits with a new system.

Kanter, Stein and Jick (1992) argued that clear cut stages offer too simplistic a view and instead describe organizational change as more fluid in nature and one that is characterized by individuals or groups exhibiting different levels of readiness for change. This researcher supports the premise that often differences exist within organizations as to a perception of how ready they are for change or where they as an organization, are in the developmental process of institutional change. That difference in perception is often between employers, employees and consumers. This proposal will also examine the

differences in perceptions between employers, including the Board of Directors, as well as between employees and consumers, identified as parents of children with and without disabilities. The difference that will be measured will be the perceptions of those four groups as to where the organization is on a developmental continuum as it relates to inclusion of individuals with disabilities.

Most people dislike change of any kind particularly when it is perceived as imposed change. Conner (1993), London (1988), and Toffler (1970), have described the stresses that are often felt by members in an organization when change occurs, one of the most common behaviors being resistance to change. There are a number of reasons for resistance to change and one of them is most certainly a sense of powerlessness. Conner (1993) backed by several decades of clinical experience as an organizational psychologist promoted acceptance of resistance as a natural and unavoidable part of the process. He further suggested that individual perceptions of the change process are influenced not only by outcome but also by the amount of influence they may have in the change process. The issue of influence in the process of change brings us back to the need that the stakeholders and the consumers need to have influence and voice in the process. The notion of voice reminds us of the imbalance of power often present in organizations that are resistant to expanding their membership's diversity. Larkin and Larkin (1994) suggested that communication is the life blood of an organization and managing change requires functional communication, more than policies or top-down directives if one's goal is to influence culture change. Andreasen, a modern day scholar who writes about facilitating social change, suggests that strategic planning is critical to any successful social marketing plan (1995). He feels it is critical that those who implement the plan

should have ownership of it and further suggests that the very process of working together to develop a strategic plan has significant effects on group cohesion and mutual respect. Surely developing inclusive organizations could be described as social marketing and these concepts of involving stakeholders, listening to their needs, planning thoughtful change and implementing and monitoring are all part of the developmental process.

Empowerment and Shared Decision Making

Power is a critical social process that is often required to get things accomplished in interdependent systems (Pfeffer, 1992). It is defined as “the potential ability to influence behavior, to change the course of events, to overcome resistance, and to get people to do things they otherwise would not do” (p. 30). Pfeffer (1992) asserted that power derives from control over resources, one’s position in the hierarchy and ties to powerful others as well as from formal authority.

Pinderhughes (1989) examined power in the mental health and social science fields and defined it as “the capacity to influence, for ones’ own benefit, the forces that affect one’s life, while the inability to exert such influence was powerlessness” (p.122). Particularly interested in cross-cultural helping relationships, she pointed out that the so-called clinical experts are in positions to interact with clients in a stereotypical domination-subordination relationship or in a relationship characterized by equality. She recommended that clinicians empower clients through the use of strategies that enable them to experience themselves as competent, valuable and worthwhile, both as individuals and as members of their cultural group. Empowerment should not have to come from a clinician; it should be part of the culture of a diverse organization.

Helgeson (1990), Kanter (1977), Pinderhughes (1989), and Shakeshaft (1987) each stressed the importance of expanding the concept of empowerment by expanding the circle of people involved in decision making, as would be seen in an advisory committee or task force on creating inclusive communities. Arredondo (1996) reminds us that by encouraging empowered participation, the participants will be more likely to give feedback about what the change should look like.

Significant change does not occur without some level of resistance at some place or point in the organization's life. Lewin (1951) developed a theory of force-field analysis that suggests that by increasing the force for change, there will be an increasing opposing force resulting in more conflict and a need to increase resources to facilitate the change. Having studied participatory action research, Lewin (1951) suggested that by involving individuals in the change process the outcome would be higher morale and more effective outcomes in terms of the desired change. Most modern day organizational consultants understand that for change to be effective the change process must be participatory (Arends & Arends, 1997; Krueger, 1988). Dunn and Swierczek (1977), having researched nearly 70 studies of organizational change, promoted collaboration and the participative approach as the most critical components of successful change.

Bennis and Nanus (1985) described the same positive outcomes when individuals in the process are empowered. Bennis (1993) restated that view by describing the importance of leaders to communicate their vision and to involve everyone in the process of change. Blake and Mouton (1981) also proposed that the most effective way to change organization norms was to include participants in defining and describing issues and problems and encourage their input in discussing strategies for change. Plunkett and

Fournier (1991) recommended that early and ongoing involvement of informal leaders in the beginning stages of planning would result in less resistance from the membership. Many organizational consultants recommend utilizing employee attitude surveys to get input about the intended organization change and suggest that positive change will result from that process. This research proposal recommends the use of employee surveys as well and will contrast those surveys with surveys from management and leadership as well as surveys from clients or consumers.

Finally, Peter Senge (1990) in writing about learning organizations described the difference between "buying into a vision", which usually means someone is selling a vision, and "enrollment" in that vision, which means that there is free choice in accepting the vision. He describes the differences between compliance to the vision on a developmental spectrum with the following gradations, from most to least. The most advanced is *commitment* when the person wants it to happen and will make it happen. The next is *enrollment*, the process of becoming part of something by choice, followed by *general compliance*, like good soldiers who see the benefit of the vision and will do everything and more. Below that level is *formal compliance*, where the person sees the benefit of the vision, does what is expected and no more, followed by *grudging compliance* where they do not see the benefits of the vision so they do enough of what is expected because they feel they have to but they are really not on board. Below this is the level of *noncompliance*, where the individual does not see the benefit of the vision and will not do what is expected. Finally he describes *apathy* when they are neither for nor against the vision (p. 219).

Senge (1990) proposed that because most organizations think linearly, they often stay at a compliance level rather than embracing a shared vision for the future that might result in systems change. He describes members as generally reacting to the current reality because they can not create their future. In contrast, he envisions empowering the entire team or membership with a commonality of purpose and a shared vision. He described a process of team learning, which involves aligning and developing the capacity of the team to create results the members truly desire. In order to do that, Senge prescribed necessary conditions of team learning including the ability to think about complex issues, open discussion and dialogue with suspension of assumptions, and a degree of "operational trust" (p. 237) when the innovative or coordinated action is necessary. Following is an example of how some learning organizations support complex change. It is taken from the literature on creating inclusive schools and is particularly suited to this research proposal as the process being evaluated is the same, namely the inclusion of children with disabilities.

Strategies for Change: Examining Diversity Initiatives

Ambrose (1987) subscribed to a formula for explaining success or failure in managing complex change within an organization. Knostner (1991) in adapting that formula suggested that at least five variables – vision, skills, incentives, resources, and action planning all factor into a formula that facilitates change. These variables which were described and defined in relation to inclusive schooling are very similar to the strategies required to manage complex change in community organizations, whether public or non-profit that commit to begin the process of creating inclusive communities. This author's experience after 8 years of working with private, public or non-profit youth organizations

is that while most have a mission statement that is intended to describe their commitment to provide services to children and their families, very few of them have reflected on whether or not that commitment is inclusive of all children and families. Seldom have they asked themselves if they have discriminated against people with disabilities, consciously or unconsciously by their restrictive admissions policies or rigid eligibility criteria. Many have not done voluntary self reflection and most attempts to change have been facilitated by external factors such as the threat of a lawsuit or negative community or media attention or perhaps their reasons to change are motivated by incentives such as donations, grants, capital improvement funds or an opportunity to draw attention to their programs and services.

Reflecting back on Knoster's (1991) variables for facilitating changes in school reform issues, they seem quite similar to the same conditions that facilitate changes in communities. Just as one of the greatest barriers to school reform is the lack of a clear and compelling vision (Schlechty, 1990), creating caring and inclusive communities in out-of-school-time hours also requires *building a vision*. Parnes (1988) used the term *visionizing* to describe the process of creating and communicating a compelling picture of a desired state and inducing others' commitment to that future. The process requires that members of the organization reconceptualize their beliefs and declare public ownership of a new view. In the same way that advocates for inclusive education stress the importance of clarifying for the entire community a vision of success based on assumptions that (1) *all* children are able to learn, (2) *all* children should be educated together in their community's schools, and (3) the school system is responsible for the unique needs of *all* children and the community is responsible to adopt that vision, this

author's vision of creating inclusive communities is based on an assumption that *all* people have value, *all* people have a right to recreation, social and leisure activities, *all* people should have choice, and *all* people have a right to experience *belonging*.

One of the ingredients for visioning is to build consensus by examining the rational for change. This can be done by sharing with others the rational for inclusion based on theory, ethics and research that validate it, while addressing members' personal concerns. Another powerful strategy for securing support for the vision of inclusion is to involve representatives of school and community stakeholder groups and allow them participation in decision making, thereby ensuring "ownership" of the resultant vision statement (Thousand and Villa, 1992). A third strategy for creating the vision is to build consensus by respecting what we expect. This can be accomplished by recognizing and publicly encouraging the staff and membership, both adult and children who are modeling and actively promoting the philosophy of inclusion.

Finally, the visionizer or change agent is critical to the process and understands that change means cultural transformation and that it may take many years. It requires commitment on their part to support and nurture that process while creating dissonance, discomfort, chaos, and a sense of urgency in the school and in the community.

Again looking at the school reform model Knostner (1991) believes that while school systems can have vision, incentives, resources and an action plan, that unless educators believe they have the skills to respond to student's need, the outcome will be anxiety and not success. The process of *skill building* requires collective instructional support, access to one another and areas of common training for all staff. The same is true in that *skill building* and confidence building is critical in programs that are just beginning to include

people with disabilities. The organization must commit to providing training to the staff, time away from work and during the work week to strategize and plan ways to learn disability awareness, develop the necessary resources, learn to do intakes with families and become skilled at knowing how and when to make accommodations. It requires some on-site technical support from parents or professionals who will assist and model best practices and it requires reinforcement and celebration when the staff is successful in its new way of doing business.

Knoster also suggests that another important ingredient to creating the change necessary to build inclusive school communities is *creating incentives* to engage people in inclusion. Thousand and Villa (1995) caution however, against traditional *extrinsic* incentives such as financial awards or honors. Sergiovanni (1990) explains that in traditional management theory, work performance often becomes contingent upon a bartering arrangement and is often not self-sustaining. In contrast, advocates for change promote *intrinsic* incentives such as recognizing ones' own effectiveness, pride in one's professional risk taking and growth, feelings of personal satisfaction and recognition from respected colleagues or team members. Sustainable change in culture is not possible without *intrinsic* incentives. This same principle is very important in creating inclusive communities. The individuals involved in the transformation must commit to and invest whole heartedly in the change because they know intrinsically, "it is the right thing to do", not because there is some extrinsic incentive to change.

Another critical piece is to have *resources for inclusion*. Looking at Knostner's reference to inclusive education, in order for change to occur, educators must have access to resources, which may be technical in nature, material, or organizational resources

including ever valuable, time (1991). The experts recommend merging resources through team-teaching arrangements which often means changing job functions or titles. It also requires administrators providing instrumental, appraisal, informational and emotional supports (Littrel, Billingsley & Cross, 1994). Other resources that can not be overlooked are students and outside partnerships which might be human, political or fiscal resources. The same is true for any other organization. There must be a commitment to provide resources to staff, whether it means hiring additional staff to support a change in ratios of adults to children, perhaps hiring a part-time inclusion or diversity coordinator and generally providing whatever necessary supports the staff needs to implement inclusive practices.

The last of the five variables in Knoster's formula for change is *action planning*. This means being thoughtful and communicative about the *process* of change and involves identifying the who, what, when and where of the process. An action plan requires participatory planning that involves stakeholders, the people who are at the core of the change. It requires intra-organizational collaboration and boundary crossing, which pays attention to the social, political, economic and cultural trends of the wider community. It also requires inter-organizational collaboration, examining internal strengths and weaknesses. Action planning involves ongoing monitoring of change, revisiting the vision, putting things in writing and finally evaluating the change and the action plan itself. An example of a process that leads to action planning is the Organizational Development Model of Inclusion (ODMI) as developed by Baron and Mitchell (1998) and it will be described in more detail in this next section. This model is particularly pertinent as it is the model from which this research study evolved.

The Organizational Developmental Model of Inclusion

The Organizational Developmental Model of Inclusion (ODMI) was developed in 1998 by Baron and Mitchell at the University of San Diego following completion of a four year initiative to institutionalize cultural diversity and create cultural competence. The university was committed to move from a monocultural institution to a multicultural institution and recognized that it would require a broader view of diversity and culture, beyond race and ethnicity. This was in response to a long self reflective period of four years to institutionalize cultural diversity and in response to recommendations from evaluators Thomas and William Parham from UCLA and UC Irvine respectfully, who in 1995 completed an evaluation of the process toward that goal. One of the outcomes was to set up a Cultural Competence Project Team (CCPT), whose job it was to craft a mission statement, goals and a working model of cultural competence to guide the University of San Diego's efforts toward inclusion.

The ODMI was a result of the University realizing that where they wanted to be in terms of cultural competence was very different from where they were and recognizing that the answer would be found in the "process", namely how to approach the task and how to strategize the plan. Using Arredondo's (1996) model for an Organizational Diversity Blueprint, they were able to identify the steps required to provide more cohesion to its inclusion effort. The Organizational Diversity Blueprint identified the following steps as critical to the process: 1) Preparing for an initiative; 2) Articulating a vision; 3) Clarifying the business motivators; 4) Gathering data; 5) Organizing the strategic plan; 6) Implementing tactics; and 7) Measuring for impact. All of these steps reinforced Parham and Parham's (1995) findings that achieving diversity successes rests

more with committing the institution to a process of change, rather than arriving at a specific point along the way.

The ODMI was designed as a conceptual model based on the premise that the creation and maintenance of an inclusionary work environment is a developmental process (Katz, 1989), and similar to Katz's developmental model, the ODMI proposed four stages of development. The distinction between the two models, however, is that the ODMI has two important dimensions at the heart of the developmental process. Baron and Mitchell (1998) described those dimensions as the degree to which the organization's leadership and membership perceive as important, the need to create and maintain a diverse and inclusionary work environment and secondly, whether the rationale to create such an environment is motivated by external factors such as access to funding or threat of lawsuits, or by internal factors such as a belief that diversity is valuable, desirable, and promotes synergy. Using those two variables Baron and Mitchell created a matrix for a developmental model that helped the organization understand where it fell and how it could move along on a developmental continuum of change. They plotted on one axis the variable *Significance of Inclusionary Beliefs* to be assessed ranging from unimportant to important, while the second axis, *Motivational Imperative*, was assessed from external to internal. Their belief was that once the inclusionary stage and range of an organization is assessed, strategic plans and specific interventions could be matched along developmental lines.

The following four stages of development were suggested by Baron and Mitchell (1998) to describe the progression of an organization's inclusionary beliefs and behaviors.

Stage 1: Exclusion. When an organization's inclusionary beliefs are of little or no importance for its leadership and membership, there is little or no motivation to change, the organization likely exhibits an exclusionary climate and there is differential treatment along with possible prejudices and discrimination. Generally the organization is structured to maintain the privilege of the dominant group with little regard for diversity. People of diverse cultural backgrounds may be allowed to participate in the organization, as long as they assimilate or exhibit behaviors that are similar to those prescribed by the dominant group. The decision to exclude may be intentional, however is often based on passive preservation of a power structure and a desire to conduct "business as usual," thus perpetuating exclusionary practices.

Stage 2: Symbolic Inclusion. This next stage often occurs when an exclusionary organization takes their first steps toward addressing diversity and inclusion because of external motivational factors or pressures. The pressures may increase the perceived importance of inclusion; however the change is often based on the desire to avoid negative consequences, such as litigation or public relations problems, or because of the opportunity of obtaining external funding or grants or for social desirability or appearance sake. This is a stage where the organization attempts to downplay differences, bring in "qualified others" in symbolic positions, while the change is generally considered cosmetic.

Stage 3: Prescribed Inclusion. This is the stage at which the organization's leadership places increasing importance on developing an inclusionary environment and the motivational imperatives to change become more internally driven. The organization begins to exhibit more tolerance for differences, recognizing that diverse people have a

place in the organization and may enhance its functioning. Groups previously excluded may begin to develop their own networks, the institution becomes more responsive to all forms of discrimination and the climate and culture changes to one that accepts and supports diversity. Concrete discussions around policies and procedures occur and the organization begins to address the need for change at all levels. This stage is a crucial transformational stage because the organization has emerging awareness of the importance of addressing diversity issues and is in a position to develop motivational imperatives that are guided by internal forces, rather than external.

Stage 4: Inclusion. This final stage occurs when an organization moves forward in placing importance on inclusionary beliefs and when motivational imperatives are internalized. The behaviors and beliefs have become grounded in the fact that the organization and its leadership truly value diversity. There is a conscious effort to recruit and retain diverse individuals and the individuals feel empowered and valued. There is a balance and congruence between the organization's norms and expressed values and its behaviors as inclusionary norms are institutionalized

Baron and Mitchell (1998) suggested that in order for the university to achieve its goal of increasing diversity, the institution would need a clearer conceptual framework to move from one point to another in the process. The Organizational Developmental Model of Inclusion closely supports a process-oriented paradigm as does the Organizational Developmental Model of Inclusion for People with Disabilities (ODMI - PWD), which is a direct adaptation created by this researcher that will be introduced and discussed in the next chapter.

Leadership and Change

Philosophers who have studied the teachings of Confucius and Aristotle know that historical accounts of leadership and its influence on society predate the Bible and modern day scholars and consultants continue to address the study of leadership as it relates to change. Some among them suggest that organizational change is initiated and guided from the top down. Foster (1989), Kotter (1990), and Rost (1991) all included change as an element in their description of leadership. Work (1996) resisted using the term leader to describe a person with organizational power and authority, however, he felt that true leadership could only exist within a social context with visions that are socially meaningful and based on standards that benefit society. He cautioned us that far too many executives in both for-profit and not-for-profit organizations are not true leaders as “true leaders should not and must not support values that perpetuate or give countenance to social injustice” (p. 75).

Beckhard and Harris (1987), Peters and Waterman (1982), Kanter (1983), and Deming (1986) are among the theorists that ascribe most real change, including culture change as driven by management. William Bennis (1989) makes a critical distinction. He defined leadership as the “management of attention through a compelling vision that brings others to a place they have not been before” (p.158). “Leaders are people who do the right thing; managers are people who do things right” (p.18). The reference to action, support's the work of Terry (1993), who suggested that the common requirement of all leadership theories is action.

Other researchers also suggest that most significant organizational change occurs

neither with a top-down nor bottom-up approach. Two concepts in current leadership theory are the importance of followers in the leader-follower dyad and the nature of the leader-follower relationship. “Leadership is exercised in order to realize purposes mutually held by both leaders and followers” (Burns, 1989, p.13). Cox (1993) defined values leadership as a transformational role that fosters the development of stakeholders while instilling a sense of mission. It is this concept of leader and followers providing leadership that the researcher intends to examine through this research proposal.

Cordeiro and Kolek (1996) describe organizations and partnerships with flattened hierarchies as also being capable of producing leaders at any level. The type of leadership they describe as emerging, depends on the situation and needs of the individual participants. This author suggests this is often what happens when all the stakeholders, parents included, are at the table designing and evaluating the process as it occurs. This type of leadership which brings together people from different organizations and agencies to collaborate and form partnerships is a necessary ingredient for providers of after school youth programs who have little or no experience outside of recreation or childcare and limited internal resources. The challenge of creating inclusive communities and providing services for children with disabilities in natural environments will require leadership, trust between the parents and providers as well as the support of others in the community. With true collaboration and strong leadership, organizations can and will facilitate the culture change that is intended.

Bringing professionals with differing skills together to meet the complex of needs of children, particularly underserved children, often requires “a societal imperative,” a deep social responsibility on the part of adults to satisfy the immense mental and physical

needs of children, coupled with boundary spanning strategies to help to resolve the complex needs of children (Sloan, 1995). Meeting these needs requires there must be boundary-spanning individuals who are adept at managing novel interdependencies among adults as their organizations become more complex (Finch, 1977, p.298). Almost all effective leaders will have boundary spanning capabilities if they are to effect change in a wider system. The final reference to leadership follows as it seems especially appropriate to the process of culture change suggested in this study.

Transformational Change

James MacGregor Burns (1978), historical biographer and leadership scholar who is best known for his references to the relationship between leaders and followers, defines transformational leadership: "Leadership over human beings is exercised when persons with certain motives and purposes mobilize, in competition or conflict with others, institutional, political, psychological, and other resources so as to arouse, engage, and satisfy the motives of followers" (p. 18). Clark and Clark (1994), summarized their view of leadership as "an activity or set of activities, observable to others, that occurs in a group, organization, or institution involving a leader and followers who willingly subscribe to common purposes and work together to achieve them" (p. 31). Depree (1992), wrote, "Performance of the group is the only real proof of leadership" (p. 140). Ronald A. Heifitz (1994), challenged this process as he described the role of leadership in terms of adaptive work where people have to learn to "address conflicts in the values they hold onto, diminish the gap between the values people stand for and the reality they face" (p.22). Creating more diverse communities, something Heifitz might refer to as a socially useful outcome, involves significant adaptive work. It requires a change in the

values, beliefs and behaviors of an organization's membership. This type of adaptive work clearly requires transformational leadership.

Another reference to transformational leadership in the literature is Tichy and Devanna (1986), as they described specific steps in identifying the process of organizational change. The steps include recognizing a need for change or revitalization, constructing a new vision and then institutionalizing change. They have identified a number of common characteristics they associate with transformational leaders. They *identify* themselves as change agents, they are courageous individuals, they believe in people, they are value-driven, they are life long learners, they have the ability to deal with complexity, ambiguity, and uncertainty and they are visionaries.

One of the most important conditions for including individuals with significant disabilities is addressing attitudes of the non-disabled persons who may have had limited or no contact or life experiences that would make them initially comfortable with people with significant disabilities. It is critical that leaders model genuinely respectful ways to greet and interact with people with disabilities. Kouzes and Posner (1993) in describing the qualities of leaders claimed that "Credibility is earned via the physical acts of shaking a hand, touching a shoulder, leaning forward to listen" (p.46). When one witnesses these physical acts in an organization that has never welcomed or supported the participation of people with disabilities, there is reason to be hopeful. That organization is moving forward on a developmental spectrum as it relates to practices being congruent with values and a newly articulated mission statement.

Conclusion

The literature review was intended to provide a historical perspective of how individuals with disabilities have been treated over the centuries and how perceptions of individuals with disabilities continue to segregate, exclude and at the very least limit their choices about what they would like their lives to look like in terms of their place in the community. The literature review examined one well documented model of inclusion, the education system that has a rich history of providing services for children with disabilities and will have direct implications for recommending systems change for organizations that provides services and programs for children in out-of-school-time hours. The chapter also references literature on organizational change and specifically diversity management as well as the impact of leadership on organizational change. A review of these four topics should provide a frame of reference to understand the proposed research. The chapter leads us to a theoretical framework that increasing diversity in any capacity requires a commitment to change and leadership to facilitate that change.

CHAPTER 3

METHODOLOGY

Introduction

This chapter describes the research design and methodology that was used in this research. The study employed a survey design that used statistical techniques to analyze data and determine the extent of differences in the perceptions of four groups of individuals considered organizational stakeholders in community youth development programs. The four groups were stakeholders from five specific Boys and Girls Club organizations in San Diego County and they represented leadership, staff, parents of children without disabilities, and parents of children with disabilities. The participants were surveyed using a modified version of the Organizational Developmental Model of Inclusion. The adapted survey tool, the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI – IWD)*, was used to measure stakeholder perceptions of where the organization rates on a developmental continuum regarding the inclusion of individuals with disabilities. The survey responses of the four groups of stakeholders were statistically compared through the use of independent sample t-tests. Demographic data was also collected from a limited number of parents of children with disabilities in an effort to employ multiple regression analysis to explain variation in individual responses. However, less than 30 parents provided the demographic data required for this analysis, and as a result, the analysis was dropped from the dissertation.

Research Questions

The following four questions guided the research for this study:

- 1) How does each group of stakeholders rate their organization on the developmental continuum of inclusion?
- 2) What, if any, discrepancies exist between the perceptions of the agency's leadership, including the Board of Directors, the Executive Director and the Director of Operations, and the full-time equivalent program staff, based on their rating of the organization on the developmental continuum of inclusion?
- 3) What, if any, discrepancies exist between the perceptions of the parents of children without disabilities and parents of children with disabilities, based on their rating of the organization on the developmental continuum of inclusion?
- 4) What, if any, discrepancies exist between the perceptions of the organization defined as leadership and program staff, and the perceptions of the consumers, defined as parents of children without disabilities and parents of children with disabilities, based on their rating of the organization on the developmental continuum of inclusion?

The following sections describe the instrument, the sample population, sites for data collection and the method of data collection and analysis.

Instrumentation

Deciding What to Measure

There is considerable support in the literature that a survey can be a very valuable tool in evaluation and measurement. Borg and Gall (1983) suggest that instruments need to have clear instructions and must be concerned with who will be asked the questions, in which case "with careful planning and sound methodology, the survey (instrument) can be a very valuable tool in education" (p. 415). Devillis (1991) recommended the first

step in designing an instrument is to clearly articulate what the researcher wishes to study. In this study, the goal was to determine if there were differences in the perceptions of organizational stakeholders as to how the organization welcomes and supports individuals with disabilities, and whether or not stakeholders felt the organization's belief system was congruent with the actual way the organization was doing business in regard to inclusion.

One popular way to ensure the reliability and validity of an instrument is to base it on one that someone else has developed (Fink & Kosecoff, 1998). They suggest that selecting an existing information collection instrument is less expensive than developing a new one and that it gives the evaluator confidence in its validity and enables the evaluator to start from a validated base and adjust to the current situation. The survey tool that was used for primary measurement in this study is called the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI - IWD)* and is a survey tool directly adapted from the Organizational Developmental Model of Inclusion (Baron & Mitchell, 1998). Patton (1982) also confirmed that one of the preferred sources for survey items was other survey items that were used for similar purposes.

Designing the Survey

The following steps describe how the survey was designed. Following a thorough literature review, the Organizational Developmental Model of Inclusion was identified as a tool to measure organizational change in higher education in relation to diversity initiatives. That survey tool was used as the model and a new survey tool created called the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI - IWD)*. Specific behavioral statements were included in the survey tool based

on a literature review that described inclusive practices in education, as well as the researcher's clinical and professional experience over the last three decades of working with individuals with disabilities and their families.

The *ODMI - IWD* was designed to ask self-reflective questions of the stakeholders in regard to their perceptions about specific conditions in the organization. The conditions represent several dimensions that are critical to the process of inclusion and are described below and identified by one or two words under specific indices in the analysis of the data section.

1. The current existing inclusion practices and representation of individuals with disabilities, labeled in the indices as ***Diversity***.
2. The existence or non-existence of differential treatment of individuals with disabilities in the organization, labeled in the indices as ***Differential Treatment***.
3. The level of congruency between espoused organizational values and behaviors, labeled in the indices as ***Congruency***.
4. The motivational imperative to change the organization in terms of including individuals with disabilities, labeled in the indices as ***Motivation***.
5. The experience of the minority or under-represented group in the organization, in this case, individuals with disabilities, labeled in the indices as ***Experience***.

This *ODMI – IWD* survey consisted of 50 behaviorally based statements that were divided into five sections representing the five indices of Diversity, Differential Treatment, Congruency, Motivation and Experience of the Minority. Each category has 10 statements in the section. For each statement, respondents were asked to rate their

agreement with the statement on a 5 point Likert Scale based on the following responses:

1 = Strongly Agree

2 = Agree

3 = Unsure

4 = Disagree

5 = Strongly Disagree.

The five sections were labeled by number 1 through 5 in order to help subjects understand that although the questions may seem repetitive, each category is distinct and important. The sections, while representing specific indices or categories, were not labeled on the survey as they might have influenced subject's responses.

Because respondents' self-reporting is sometimes suspect for fear of providing socially unacceptable responses (Porter & McKibbin, 1988), participants were assured anonymity during data collection in the hope they would be as truthful as possible with their responses. While the item pool may seem particularly redundant, Devillis (1991) reminds us that redundancy is necessary as it serves as "a foundation of internal consistency reliability which, in turn, is the foundation of validity" (p.60).

Sampling Plan

Sites for Data Collection

Using purposive sampling techniques, data was collected at five mid-large size Boys & Girls Clubs in San Diego County. Similar organizations were selected to ensure some cultural consistencies and the geographic area was chosen to minimize regional differences. The organizations were similar in nature of programs and services provided, including the fact they all serve children from 6 – 18 years in what is considered to be

out-of-school time hours and all are license - exempt programs meaning they are not monitored by the Department of Health and Human Services. The children were diverse from a gender, race, and ethnicity perspective, but similar in that most came from middle-class or socio-economically disadvantaged homes or neighborhoods. While the clubs all have similar mission statements, a uniform tag line, and common organizational structures as a result of being members of the national organization, The Boys & Girls Clubs of America, they have distinct internal cultures, different leadership styles and different types and amounts of resources. Additionally, it was assumed that the participating organizations will be at various stages in the developmental process of including children with disabilities.

Participants

The target population consisted of four distinct groups of stakeholders at each site. The first group of stakeholders was the organization's leadership, which included the Board of Directors, the Executive Director, and the Director of Operations. The second group of stakeholders included full-time equivalent program staff as well as middle managers. The third group included parents of children without a disability (PCWOD), sometimes referred to as parents of typically developing children. The fourth and final group of stakeholders was the parents of children with disabilities (PCWD). The researcher determined that while the survey would be given to everyone in each of the above categories, the minimum number of responses determined from each organization was set at 25 responses and the minimum number from each stakeholder group would be two responses.

Survey Procedures

Before collecting data, the survey was piloted with 10 individuals who were either adults with disabilities, parents of children with disabilities, parents of children without disabilities, or individuals who were, or are, currently either providers or in leadership positions at children or youth development programs. In other words, the pilot group included persons who would be equivalent to the stakeholder groups in the actual study. Upon evaluating their responses and suggested feedback, the instrument was adapted and finalized with only minor changes. The survey, a consent form, and a sampling plan were sent to the Institutional Review Board at the University of San Diego for review and upon approval, the research commenced.

The research study involved a one-time administration of the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI-IWD)* (Appendix B). In January and February, 2005, a letter of introduction (Appendix A) and a sample survey were mailed to the Executive Director of five specific Boys & Girls Clubs in San Diego County that were known to have included at least several children with disabilities in the past. Prior to this mailing, there had been several telephone calls and/or electronic mails to the Executive Director at each organization to explain in detail the purpose of the study, the intended participants, and the required expectations of them and their organizations. Only one club refused to participate because of a major capital campaign so another smaller club in the county was asked to participate and be the final club in the study. Once the agencies had agreed to participate, the researcher attempted to make an appointment to introduce the surveys to the leadership and staff stakeholder groups at a regularly scheduled Board or staff meeting. Specific changes were made

following personal or telephone contact with each club and that is reported below under the description of how the data was collected. Each of the organization's surveys included a small header on the top of the page to identify which club and stakeholder group they represented. In addition, the surveys for parents were on different colored paper so that they could be identified by club when the data was being analyzed.

Board and Leadership Surveys

As a courtesy to the Executive Director, the researcher asked permission to introduce the surveys and give a brief description of the research study (Appendix D) to the Board of Directors at a regularly scheduled board meeting in January, February or March, 2005, at each of the five clubs. While the researcher's intent was to complete the data collection in this manner, and while all Executive Directors agreed to participate in the study, four of the five Executive Directors stated that their Board meetings were very busy and that they could not include the personal request during the meeting. They expressly asked if the survey could be mailed electronically or by mail to their board members and assured that they would personally encourage them to complete and return the surveys to the researcher. At Club 1, the Board President did invite this researcher to introduce herself, describe the survey and pass the surveys out to the board members. Fourteen of the members completed the surveys during the meeting and returned them to the researcher immediately upon completion, while three others mailed the surveys in a self addressed stamped envelope to the researcher within several days of the meeting. All respondents were assured anonymity in both the consent form and in the personal presentation.

Because the researcher needed to assure anonymity to the subjects that would take the

survey online and since that would mean not having access to email addresses, an on-line survey company, *Survey Monkey* was used to collect the data. An introduction to the survey, consent form and the entire survey was available on the web (Appendix C). A final request for additional board surveys from Club 2 and Club 5 was made in early July, 2005 as response rate was low from those clubs and the researcher wanted better sample size comparisons between the stakeholder groups.

Staff Surveys

Initially the Executive Director of each organization was asked to invite this researcher to a general staff meeting during February or March, 2005, when the majority of the full time equivalent staff would be present. In fact only two clubs, Club 1 and Club 3 invited me to attend a staff meeting and present the survey in person. The other clubs chose to disseminate the survey electronically through the same on-line survey provider (Survey Monkey) since the leadership felt it would yield the highest rate of response, particularly if the request to complete the survey came directly from management. At the two clubs that the data was collected in person the method was as follows. The researcher introduced herself, explained the purpose of the study, answered questions from the staff, and then distributed a request for support (Appendix D) and the surveys to full time equivalent staff. The researcher reviewed instructions and asked the participants to either return the surveys in self-addressed stamped envelopes to the researcher's home within one week or they were collected as staff members exited the room. The researcher also, with permission, left surveys with self-addressed stamped envelopes in the mailboxes of other full time equivalent staff that were not present at the meeting. The staff members were thanked for their cooperation in completing and

returning the surveys in the requested time line. The Executive Director or Inclusion Coordinator was asked to follow up with an internal memo or email or remind staff at the next staff meeting to return the surveys to the researcher in the self-addressed stamped envelope. The staff was assured at that meeting and in written communication that the only person who would see the surveys would be the researcher, so that there was no possibility that their responses would be revealed to management, leadership or parents. The researcher did agree, however, to share the cumulative results of all five clubs with the management and leadership after the data was analyzed.

Family Surveys

The Inclusion Coordinator, Diversity Coordinator or a Program Director at each of the five clubs was originally asked to give the names and addresses of all the families of children with disabilities that they have record of serving and/or are currently serving, as well as the names and addresses of all children without disabilities who were or are co-enrolled in activities at the club with children with disabilities. Because the number of children with disabilities would be significantly less than the number of children without disabilities and because those parents would likely be more motivated to complete and return the survey, there were two to three times as many surveys disseminated to parents of children without disabilities. This was intended to ensure that the number of responses would be similar for both groups of parents. The researcher's intent was to mail the survey (Appendix B) and a self-addressed stamped envelope to each of these families with a cover letter (Appendix E) explaining the researcher's background and stressing the importance of completing the survey and attachments.

Unfortunately, although this method of dissemination was initially agreed to, it was

not approved by the organization because of restrictions regarding confidentiality and release of names to persons outside the club. The site supervisors suggested that the only way they could disseminate the surveys was to have the surveys given to them so that they could hand deliver the surveys with consent forms to the families of both children with and without disabilities. As a result, this researcher emailed or hand-delivered copies of the surveys complete with appropriate headers identifying club and stakeholder group to each of the five Boys and Girls Clubs participating in the study.

Parent participants were asked to complete and return the surveys and demographic information forms in a self-addressed stamped envelope to the researcher's home or in a sealed envelope to a box for collection at the club where the researcher either picked up the surveys or a Director mailed the surveys to the researcher's home. Almost all clubs were required to remind parents by phone, in person or with a note home to request parents complete and return the surveys.

Method of Analysis

Once the surveys were completed by participants and collected by the researcher, they were dated, given individual identifying numbers, coded by agency and stakeholder group, and separated by agency for analysis. Leadership was assigned an identifying code number 1, while staff was identified by code number 2. Parents of children without disabilities were assigned code number 3 and parents of children with disabilities were assigned code number 4. Agencies were coded alphabetically and numbered for anonymity.

Any blank responses on the surveys were replaced by the mean response to that question from those responding to that particular question in the same club. This

correction procedure was limited to three responses in each of the five sections of the survey or ten total responses, whichever was lower. Surveys that had more than ten blank responses were discarded and not included in the study.

Within each survey, the responses were aggregated by section and a series of five indices created that reflected the individual's perception of where the organization was rated on the developmental continuum. A higher value for each of the indices represents a more advanced developmental rating in terms of the inclusion of individuals with disabilities.

To address the first research question, the means and standard deviations for the five sectional scores and the overall score was presented for the organizations as well as for the four groups surveyed within the organizations. To answer the second research question, independent sample t-tests were used to statistically test for differences between the *Leadership*, including the Board of Directors, the Executive Director and the Director of Operations, and the *Staff*, defined as full-time equivalent program staff. Similarly, question three statistically compared the responses of the *Parents of Children without Disabilities* and the *Parents of Children with Disabilities*. The fourth research question statistically tested for discrepancies between the responses of the combined leadership and staff, and the combined groups of parents, by defining two new variables. The new variables were called *Organization* (leadership and staff), and *Consumers* (parents of children without disabilities and parents of children with disabilities). For all three research questions, the $p = .05$ level of confidence was used in the tests of statistical significance.

Protection of Human Subjects

Prior to the study, the researcher requested permission from the Institutional Review Board at the University of San Diego to conduct the surveys and commence with data collection. Informed consent forms were included in all hard copy surveys and/or sent as email attachments to each and every person that was asked to complete the survey. The online survey also included a yes/no question to participants asking their permission to use their responses in the study. The nature of the study suggested that there would be minimal risk to participants beyond the demands on their time. The completion of the surveys and the demographic information was, and will be, kept confidential - however the participants were told the results of the study would be made available to any of the organizations or interested participants at completion of the study. The researcher explained that there may be a minimum of discomfort for some participants in that the survey does inquire into personal beliefs and perceptions, however assured them that there would be absolutely no risk to the participants that their responses would be shared with others in their organization. Finally participants were assured that the surveys would be kept in a locked cabinet for up to two years at which time they will be destroyed.

Summary

This chapter introduced the research questions, the design and methodology for disseminating the survey and the method of data analysis. It described how the instrument for this study was designed and explained the value of having a self-assessment tool that would measure the perceptions of different groups of

stakeholders in the organization as to where the organization is rated on a developmental continuum of change. That self- assessment process is the foundation for developing a strategic plan toward the desired end, which is meaningful inclusion of individuals with disabilities as members of the organization.

CHAPTER 4

FINDINGS

Introduction

This chapter presents the results of the data collected from the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI – IWD)* survey described in Chapter 3. The purpose of the study was to examine the perceptions of stakeholders in five not-for-profit youth development organizations that are currently in the process of including children and youth with disabilities in their recreation and after school programs. The results of this analysis are described in three sections. The first section describes the sampling frame, procedures and response rates. The next section describes how the data were analyzed, followed by the inferential findings. The final section summarizes the research results and describes the specific differences that occurred between stakeholders within individual organizations and when the five organizations were combined.

Survey Procedure

Sampling Frame

The sampling frame for this study included four distinct groups of stakeholders in five mid-large size Boys and Girls Club organizations in San Diego County. The clubs chosen were a purposive sample drawn from nine clubs in the county as all five organizations were known to have a history of serving children and youth with disabilities. The five clubs combined represent 45 physical sites and serve approximately 30,000 children and youth each year.

The stakeholders in this study included the *leadership*, defined as the Executive Director, the Director of Operations and the volunteer Board of Directors, the *staff*, who are full-time equivalent program personnel who have direct contact with children and youth, and two groups of parents -- *parents of children without disabilities*, and *parents of children with disabilities*, who were members of the clubs.

Procedures

Initial contact was made with each organization by a telephone call to the Executive Director explaining the study and requesting the club's participation. Only one club from the first request declined to participate and that club was replaced by another club drawn from the purposive sample. Once the clubs had agreed to participate in the study a formal letter of introduction (Appendix A) and a sample of the survey (Appendix B) was mailed and also emailed to the Executive Director of each organization. When the agencies formally consented to participate, the researcher called to schedule an appointment to introduce the survey in person to the Board of Directors and the staff at the organization. Because of scheduling conflicts and time limitations, three of the five Executive Directors asked that the surveys be delivered to the club for distribution by their staff and also that they be made available in electronic form for staff and Board of Directors.

Appointments were made at Club 1 and Club 3 to introduce the survey at both the Board of Director's meeting and at the staff meetings. The surveys and consent forms (Appendix D) were collected by the researcher immediately after the meetings. The researcher contracted with an electronic survey company, *Survey Monkey*, redesigned the survey in web form (Appendix C), posted it on the website and sent the link to the Executive Directors and Director of Operations at each of the three remaining

organizations, who took responsibility for forwarding the link to their board of directors and staff with a request that they complete the survey. The survey was made available for two months online and several reminders were sent from the Executive Director and the Director of Operations reminding the board and staff to complete the online survey if they had not done so. Once the electronic surveys were completed, they were coded for club and stakeholder group, exported to an excel database and transferred to SPSS 13.0 data base for analysis.

At all five organizations, parent packets were distributed in person to all prospective families by the Program Director and /or the Inclusion or Diversity Coordinator. The packets which included a cover letter and consent form (Appendix E), survey questionnaire (Appendix B), and self-addressed stamped envelope, were given to all families of children with disabilities and to a limited number of families of children without disabilities who attended programs at the clubs during the same hours as the children with disabilities. Surveys were returned in self-addressed stamped envelopes to the researcher or were returned to the club in sealed envelopes, held by the Program Director, and picked up in person by the researcher.

When all surveys had been collected by the researcher, they were given individual identifying numbers, coded by agency and stakeholder group, and were dated and separated by agency for analysis. Leadership was assigned an identifying code number 1, while staff was identified by code number 2. Parents of children without disabilities were assigned code number 3 and parents of children with disabilities were assigned code number 4.

Any blank responses on the surveys were replaced by the sample mean for all those that responded to that particular question on the survey from the same organization. The mean replacement of blank responses was limited to three responses in each of the five sections of the survey or ten total responses, whichever was lower. There were three surveys with more than ten blank responses which were discarded and not included in the study.

Respondents' answers were recorded and aggregated into five sections of the survey that represented specific behaviors and characteristics of the organization. These five sections are labeled as follows: 1) *Diversity* - actual presence of individuals with disabilities in the organization, 2) *Differential Treatment* - perceived treatment of individuals with disabilities in the organization, 3) *Congruency* – level of congruency between the organization's espoused values and their actual practices, 4) *Motivational Imperative* - whether or not there was an external or internal motivation for the organization to include individuals with disabilities, 5) *Experience of the Minority* - perceived experience of the individuals with disabilities who are members of the organization. The five sections were totaled individually and also were combined to reflect the overall survey score that measured the stakeholders' perception of where the organization was rated overall on a developmental continuum of inclusion. The mean value was determined for each section as well as for the combined survey, with higher scores suggesting that the organization was further along a developmental continuum in terms of the inclusion of individuals with disabilities as demonstrated by practices, attitudes and real experiences of those individuals.

After the raw data was entered into SPSS 13.0 by individual identifier, organizational identifier and stakeholder identifier, the decision rules discussed earlier for missing data was invoked so that the data set was clean and ready for analysis.

Response Rates

Once surveys with missing data were removed, the total number of usable survey responses for the *Organizational Developmental Model of Inclusion (ODMI – IWD)* was 216. Of the 216 surveys returned, 107 (49.5%) were from the organization (*leadership and staff*) and 109 (50.5%) were from consumers (*parents of children without disabilities and parents of children with disabilities*). The number of surveys collected electronically from the online service, *Survey Monkey*, was 62 (28.2%) and the number of hard copy surveys returned by mail or picked up in person from the organization was 154 (71.8%).

Of the 107 completed surveys received from the organizations, the response from leadership was 44 (41.1%) while the response from staff was 63 (58.9%). Of the 109 completed survey responses received from parent consumers, 67 (61.5%) were from parents of children without disabilities and 42 (38.5%) were from parents of children with disabilities. Parents of children without disabilities are represented in the following tables as *Parents CWOD* and parents of children with disabilities are referred to in the tables as *Parents CWD*.

The number of returned surveys from individual clubs ranged from 27 to 68 and the range from stakeholder groups within clubs ranged from 2 to 26 participants. When all of the groups were combined, the two clubs that had the lowest response rates were Club 4 at 13.0% and Club 5 at 12.5 %. Interestingly, these clubs were the ones with the least experience and shortest history of including individuals with disabilities in the sample.

The three clubs with a longer history of practicing inclusion had higher response rates with Club 1 at 19.9%, Club 2 at 31.5% and Club 3 with 23.1%. The club with the highest response rate (Club 2) was due entirely to the leadership and persistence of the Director of Operations to encourage staff, board and families to return surveys. Frequency distribution and response rates by stakeholders for each club are reported in Table 1.

Table 1: Frequency Distribution and Response Rates of Stakeholders by Club

Organization	Stakeholder Group	Responses	Percent of Club Response	Total Percent of Responses
<u>Club 1</u>	Leadership	14	32.5	19.9
	Staff	10	23.3	
	Parents CWOD	12	27.9	
	Parents CWD	7	16.3	
	Total Club Responses	43		
<u>Club 2</u>	Leadership	11	16.2	31.5
	Staff	16	23.5	
	Parents CWOD	26	38.2	
	Parents CWD	15	22.1	
	Total Club Responses	68		
<u>Club 3</u>	Leadership	8	16.0	23.1
	Staff	19	38.0	
	Parents CWOD	11	22.0	
	Parents CWD	12	24.0	
	Total Club Responses	50		
<u>Club 4</u>	Leadership	8	28.6	13.0
	Staff	8	28.6	
	Parents CWOD	6	21.4	
	Parents CWD	6	21.4	
	Total Club Responses	28		
<u>Club 5</u>	Leadership	3	11.1	12.5
	Staff	10	37.0	
	Parents CWOD	12	44.5	
	Parents CWD	2	7.4	
	Total Club Responses	27		

Analysis of Data

Data analysis was done using both descriptive statistics and independent sample T-tests designed to test for differences in the means between clubs as well as between stakeholders. These tests were conducted for each of the 5 indices of the survey instrument as well as for the overall survey.

As discussed in the previous chapter, the surveys were designed to measure perceptions of stakeholders regarding the importance that the organization's leadership ascribed to welcoming and supporting individuals with disabilities, and whether or not the rationale to create a more inclusive community was motivated by external factors (e.g., access to resources and/or funding (positive motivator) or a threat of a law suit or negative publicity (negative motivator) or by internal factors (e.g., a belief that including individuals with disabilities is valuable and desirable.)

In the sections that follow, the results of the data analysis is presented by research question, with the final three questions comparing different groups of stakeholder perceptions.

Research Question 1

How does each group of stakeholders rate their organization on the developmental continuum of inclusion?

To answer this question, all stakeholders were asked to rate their response to 50 behaviorally-based statements that were divided into five (unlabeled) sections on the *Organizational Developmental Model of Inclusion (ODMI – IWD)* survey. For each statement, respondents were asked to rate their agreement with the statement on a 5 point

Likert scale based on the following responses, with the higher the number on each question representing a more advanced stage of inclusion within the organization.

1 = Strongly Agree

2 = Agree

3 = Unsure

4 = Disagree

5 = Strongly Disagree

Responses to the statements were then aggregated within section so that indices were produced that represented the mean scores for each of the five sections – *Diversity*, *Differential Treatment*, *Congruency*, *Motivational Imperative*, and *Experience of the Minority*. In addition to these five indices, an overall score was produced that represented the simple average of all five indices. These averages for each club were then converted to percentage scores, thereby making comparisons between clubs easier. While all five club averages were within the 70th percentile, there was a distinct difference noted. The two clubs with the longest history of practicing inclusion were Club 1 at 78% and Club 3 at 76%, while the three remaining clubs with a shorter history of inclusion, had averages of Club 2 at 73%, Club 4 at 72%, and Club 5 at 73%.

Table 2 presents the comparison of the means of all stakeholders for each of the five clubs and between all four stakeholder groups across clubs. Variables significant at the $p = .05$ level are marked with a single asterisk while variables significant at the $p = .01$ level are marked with a double asterisk. Occasionally a comment is made regarding variables that are significant at the $p = .10$ level, but not the $p = .05$ level.

Table 2: Comparison of the Means of Stakeholders for the Combined Survey
Score Between Clubs and Across All Clubs

	<u>Club 1</u>	<u>Club 2</u>	<u>Club 3</u>	<u>Club 4</u>	<u>Club 5</u>	<u>All Clubs Combined</u>
<i>Leadership</i>	41.79	40.47	42.33	38.63	36.87	40.02 **
<i>Staff</i>	37.80	37.59	39.04	33.33	38.44	37.28
<i>Parents CWOD</i>	35.31 *	36.58 **	33.96	35.37	36.70	35.58
<i>Parents CWD</i>	41.66	31.21	36.75	37.40	33.40	36.08
All Stakeholders	39.14	36.46	38.02	36.18	36.35	

As shown in Table 2, there did seem to be a pattern, in that for four of the five clubs, the leadership reported higher scores on the *ODMI –IWD* than the staff. Club 5 was the only exception, and this might be explained by the limited number of responses from leadership. For example, that club had 13 responses from the staff and only three surveys returned from the leadership, two of which were executive staff. Only one board member responded while several others stated that they were not comfortable enough to complete the survey since they knew nothing about inclusion at the club.

When all clubs were combined, the *leadership* perceptions were significantly different than the *staff* perceptions, as well as being significantly different than the perceptions of the *parents of children without disabilities* and the *parents of children with disabilities*. At three of the five clubs, the parents of children with disabilities rated the organization further on the developmental continuum than the parents of the children without

disabilities. These three clubs, have in fact, hired an inclusion or diversity coordinator specifically charged with responsibility for children with disabilities. The parents of children with disabilities at those clubs appear to be at least moderately, and in some cases, very pleased with their child's experience and the organization's responsiveness to including their child.

While Table 2 reflected differences among all stakeholders and all clubs, the remainder of the tables in this chapter report more specifically on the differences in perceptions among specific groups of stakeholders so as to answer the final three research questions.

Research Question 2

What, if any, discrepancies exist between the perceptions of the agency's leadership, including the Board of Directors, the Executive Director and the Director of Operations, and the full-time equivalent program staff, based on their rating of the organization on the developmental continuum of inclusion?

Mean values were calculated for each of the five indices for the leadership and the staff within each of the organizations and for all organizations combined. This information is presented in Table 3. Significant differences between the two groups are indicated with an asterisk/s. The same symbols were used in all the tables in this chapter, with a single asterisk to indicate significance at the $p = .05$ level and a double asterisk to indicate significance at the $p = .01$ level.

Table 3: Comparison of Index Means for Leadership and Staff for all Clubs Individually and for all Clubs Combined with Significance Difference Noted

Index	Diversity	Differential Treatment	Congruency	Motivational Imperative	Experience of Minority
Club 1					
Leadership	35.86	42.78	45.14 **	42.71	42.42
Staff	35.70	38.00	38.10	38.90	38.30
Club 2					
Leadership	35.91	41.09 *	42.35 *	42.09 *	40.82
Staff	36.75	37.63	37.44	37.56	38.56
Club 3					
Leadership	39.37	43.00	44.00	43.12	42.12
Staff	35.47	39.47	39.21	40.79	40.26
Club 4					
Leadership	37.50	40.87 *	40.12	38.00	36.62
Staff	32.50	34.00	33.25	33.50	33.38
Club 5					
Leadership	34.00	35.00	41.33	38.00	36.00
Staff	35.30	39.00	38.00	39.60	40.30
All Clubs Combined					
Leadership (n = 44)	36.60	41.25 **	43.09 **	41.45 *	40.48
Staff (n = 63)	35.94	38.02	37.76	38.56	38.65

* $p \leq .05$ ** $p \leq .01$

The null hypothesis was that there was no difference in the perceptions of the leadership and the staff of the organization. When comparisons were made between the clubs, the hypothesis was rejected for three of the five clubs. For example, Club 1 showed a difference in the indices of *Congruency* at the $p = .01$ level. Club 2 showed a difference in three indices including *Differential Treatment* at $p = .02$, *Congruency* at $p = .01$, and in *Motivational Imperative* at $p = .03$. Club 4 showed a difference in *Differential Treatment* at $p = .02$ and the difference in two other indices was nearly significant at the $p = .05$ level. Those indices were *Diversity* at $p = .06$ and *Congruency* at $p = .06$.

Differential Treatment and *Congruency* were the two indices where there was the most difference in perceptions within clubs. In two of the five clubs, the leadership did not perceive individuals with disabilities were treated differently than the general population and they also believed that their practices were congruent with their espoused values. Interestingly, the staff perceptions at those organizations were that individuals with disabilities were treated differently and that there was a lack of congruency between organizational practices and espoused values.

When the leadership and staff surveys were combined for all clubs, the null hypothesis that there was no difference in perceptions between *leadership* and *staff* was also rejected for three of the indices. As shown in Table 3, these indices were - *Differential Treatment* at $p = .00$, *Congruency* at $p = .00$ and *Motivational Imperative* at the $p = .02$.

Research Question 3

What, if any, discrepancies exist between the perceptions of parents of children without disabilities and the parents of children with disabilities, based on their rating of the organization on the developmental continuum of inclusion?

Mean values were calculated for each of the five indices for *parents of children without disabilities* (PCWOD) and for *parents of children with disabilities* (PCWD) within each organization and for all organizations combined. Table 4 presents the comparison of these means and significant variables are marked with a single or double asterisk, depending on their level of statistical significance.

Table 4: Comparison of Index Means for Parents of Children without Disabilities (PCWOD) and Parents of Children with Disabilities (PCWD) for All Clubs Individually and for all Clubs Combined with Significance Difference Noted

Indices	Diversity	Differential Treatment	Congruency	Motivational Imperative	Experience of Minority
Club 1					
Parents CWOD	33.83	36.83	35.18 *	36.09 *	34.75 **
Parents CWD	37.00	43.00	43.14	43.00	42.14
Club 2					
Parents CWOD	35.07 **	38.04 **	36.42 **	36.42 **	36.96 **
Parents CWD	29.73	31.73	30.27	30.27	30.13
Club 3					
Parents CWOD	33.64	30.72	33.91	35.09	36.45
Parents CWD	35.83	34.42	38.00	41.25	34.25
Club 4					
Parents CWOD	33.00	38.17	36.67	38.17	33.83
Parents CWD	35.83	38.00	38.33	38.00	36.83
Club 5					
Parents CWOD	35.00	36.50	37.17 *	37.41 **	37.42
Parents CWD	31.50	38.00	29.50	31.50	36.50
All Clubs Combined					
Parents CWOD (n = 67)	34.42	36.36	35.95	36.21	36.28
Parents CWD (n = 42)	33.64	35.81	35.74	37.83	34.57

* $p \leq .05$ ** $p \leq .01$

When comparisons were made between clubs, the null hypothesis used was that there was no difference in the perceptions of parents of children without disabilities and the parents of children with disabilities. This hypothesis was rejected for three of the five clubs although the direction of difference was not consistent. For example, Club 1 showed significant differences in three of the indices - *Congruency* at $p = .01$, *Motivational Imperative* at $p = .05$, and *Experience of the Minority* at $p = .01$. In this organization, the one with the longest history of inclusion, the parents of children with disabilities consistently rated the organization further along the developmental continuum than the parents of children without disabilities. On the contrary, the other two organizations showed statistical differences, although the differences were in the opposite direction. Club 5 showed statistical differences in *Congruency* at $p = .02$, and in *Motivational Imperative* at $p = .00$. The most dramatic differences were in Club 2 which showed significant differences in all five indices. Those differences were *Diversity* at $p = .00$, *Differential Treatment* at $p = .01$, *Congruency* at $p = .01$, *Motivational Imperative* at $p = .01$, and the *Experience of the Minority* at $p = .01$.

Taken together, these scores suggest that there were indeed differences in the perceptions of parents of children with, and without, disabilities. However, the fact that in two of the clubs the parents of children without disabilities rated their club further along the developmental continuum than the parents of children with actual disabilities may be due to these parents associating the mere physical presence of children with disabilities as equating to inclusion. In any event, the parents of children with disabilities presumably are in a better position to determine the level and quality of inclusion than any other group. In fact, in two of the other clubs where the organizations had committed to hire

inclusion coordinators, the parents of children with disabilities believed that their clubs were further along the developmental continuum than the parents of children without disabilities although the differences were not significant. Not surprisingly, in the club with the longest history of practicing inclusion and with the strongest leadership, the parents of children with disabilities believed that their club was clearly further along the developmental continuum than the parents of children without disabilities as noted by significant differences in three of the indices.

While there was a significant difference in the perceptions between parents of children without disabilities and parents of children with disabilities in specific indices in three of the five clubs, the findings were not the same when all clubs were combined. Because of the differences in directionality presumably based on parent's perceptions of what constituted inclusion, the results were fairly evenly split between the parent groups. As a result, there were no significant differences in any of the five indices between the parents of children without disabilities and the parents of children with disabilities when all five organizations were combined.

Research Question 4

What, if any, discrepancies exist between the perceptions of the organization, defined as leadership and program staff, and the perceptions of the consumers, defined as parents of children without disabilities and parents of children with disabilities, based on their rating of the organization on the developmental continuum of inclusion?

Again mean values were calculated for each of the five indices for the newly defined groups of stakeholders. In research question 4, the first two stakeholder groups, leadership and staff, were combined into one and called the *organization* and the last two

stakeholder groups, parents of children without disabilities and parents of children with disabilities, were also combined as one and re-labeled *consumers*. Table 5 presents the comparison of the means between the *organization* and the *consumers* within clubs as well as between those stakeholders when all clubs are combined.

Table 5: Comparison of Index Means for the Organization and the Consumers for All Clubs Individually and for All Clubs Combined with Significant Difference Noted

Indices	Diversity	Differential Treatment	Congruency	Motivational Imperative	Experience of Minority
Club 1					
Organization (n = 24)	35.79	40.79	42.21 *	41.13	40.71
Consumers (n = 17)	34.35	37.88	37.50	37.50	36.59
Club 2					
Organization (n = 23)	36.70 **	38.26 **	38.74 **	38.96 **	39.39 **
Consumers (n = 41)	33.12	35.73	34.17	34.17	34.46
Club 3					
Organization (n = 27)	36.63 *	40.52 **	40.63 **	41.48	40.81 **
Consumers (n = 23)	34.78	32.65	36.04	38.30	35.30
Club 4					
Organization (n = 16)	35.00	37.44	36.69	35.75	35.00
Consumers (n = 12)	34.42	38.08	37.50	36.50	35.33
Club 5					
Organization (n = 13)	35.00	38.15	39.38	39.23	39.30 *
Consumers (n = 14)	34.50	36.71	36.07	36.57	37.29
All Clubs Combined					
Organization (n = 107)	35.94 **	39.46 **	39.95 **	39.75 **	39.40 **
Consumers (n = 109)	34.12	36.15	35.87	36.84	35.62

* $p \leq .05$ ** $p \leq .01$

When the responses of the organization were compared to the responses of the consumers of the organization, the null hypothesis that there was no difference in the perceptions of the organization and the consumers was rejected for four of the five clubs. Club 1 showed statistical differences in one index -- *Congruency* at $p = .03$ and nearly significant difference in *Experience of the Minority* at $p = .09$. Club 2 showed significant differences in all indices with *Diversity* at $p = .01$, *Differential Treatment* at $p = .00$, *Congruency* at $p = .01$, *Motivational Imperative* at $p = .01$, and *Experience of the Minority* at $p = .01$. Club 3 also showed significant differences between the organization and the consumers in *Diversity* at $p = .04$, *Differential Treatment* at $p = .00$, *Congruency* at $p = .01$ and *Experience of the Minority* at $p = .01$. There was also nearly significant difference in *Motivational Imperative* at $p = .07$. Club 5 showed statistically significant difference in *Experience of the Minority* at $p = .04$ and a nearly significant difference in *Motivational Imperative* at $p = .06$. Club 4 did not show any significant differences in any category.

When clubs were analyzed individually there were differences noted in four of the five clubs. However, when all clubs were combined and the number of stakeholders was nearly even between the organization ($n=107$) and the consumers ($n + 109$), the null hypothesis that there was no difference in perceptions between the organization and the consumers was soundly rejected in that there was a very significant difference in all five indices. Those differences were as follows: *Diversity* at $p = .01$, *Differential Treatment* at $p = .01$, *Congruency* at $p = .00$, *Motivational Imperative* at $p = .00$, and *Experience of the Minority* at $p = .00$.

Summary and Discussion

The *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI – IWD)* survey was administered to 216 participants, all considered stakeholders in five not-for-profit youth development organizations, specifically Boys & Girls Clubs in San Diego County. The survey consisted of 50 statements that were divided into 5 separate categories (called indices) and each index reflected specific conditions within the organization. Those conditions included whether or not there were individuals with disabilities represented in the organization (*diversity*), whether those individuals experienced differential treatment in the organization (*differential treatment*), whether or not the organization's espoused values were congruent with their practices (*Congruency*), whether the organization's motivation to include individuals with disabilities was for intrinsic benefit or because of extrinsic motivation (*Motivational Imperative*), and finally what the perceived experience was like for the individuals with disabilities who might be represented in the organization (*Experience of the Minority*). The stakeholders who responded to the survey included the organization's leadership, staff, parents of children without disabilities and parents of children with disabilities.

The responses to the first research question suggest that there does appear to be a consistent pattern in that the leadership in four of the five clubs perceived that their organization was further along a developmental continuum of inclusion than the staff. There was also a tendency in that in four of the five clubs, the staffs' perceptions were that the organization was further along a developmental continuum of inclusion than the parents of children without disabilities and in three of the five clubs staff perceptions were higher than those of parents of children with disabilities. There was less agreement

between the parents of the children without disabilities and the parents of the children with disabilities as to how far along the organization was on a developmental continuum of inclusion and there does seem to be a reason for the lack of agreement. The three clubs where parents of children with disabilities rated the organization further along the developmental continuum were in fact the three clubs with the longest history of including children with disabilities and where there was a more formal process of welcoming and supporting individuals with disabilities.

The responses to the second research question suggest that there were statistically significant differences in perceptions between the *leadership* and the *staff* in three of the five clubs as to how far along the organization was on a developmental continuum of inclusion. The *Differential Treatment* index was significantly different for two clubs as was the *Congruency* index, while the *Motivational Imperative* index was significantly different in one other club.

When all clubs were combined there were significant differences in *Differential Treatment*, *Congruency between Espoused Values and Practices*, and *Motivational Imperative*. The two indices where there were no significant differences, suggest that the perceptions regarding the actual presence of organizational diversity and the experience of individuals with disabilities within the organization was not different between *leadership* and *staff*. However, there was a very real difference in the perceptions of *leadership* and *staff* about how differently individuals with disabilities were treated in their organizations, whether or not there was congruency between their organization's espoused values and practices, as well the what the motivational imperative of their organization was to include individuals with disabilities. The *leadership* consistently

believed the organization was further along a developmental continuum of inclusion than the *staff* did on those three critical measures of inclusion.

In response to the third research question regarding differences in perceptions between parents of children without disabilities and parents of children with disabilities, when examined by club, the null hypothesis of no difference was rejected for three of the five clubs while the fourth and fifth club did not show any significant differences.

However, when all clubs were combined, the results of the analysis showed that there were no significant differences in perceptions between the parent groups. The reason for this was that in three of the five clubs, the parents of children with disabilities appeared to be at least moderately satisfied and in some cases, very satisfied with their child's experience and therefore rated the organization further along the developmental continuum of inclusion. Their children were members in the clubs with the longest history of inclusion and also those that had a formal process for welcoming and supporting individuals with disabilities. It should be noted that in the two organizations that did not have much history of practicing inclusion, the parents of children without disabilities seemed to perceive the organization as further along the developmental continuum simply because they saw children with disabilities at those facilities. That would likely explain their ratings being higher than the parents of children with disabilities, who in fact did not perceive the organization to be very far along a developmental continuum of inclusion in regard to practices and organizational postures and behaviors.

The fourth and final research question was intended to determine if there were differences in perceptions between the *organization*, defined as leadership and staff, and

the *consumers*, defined as parents of children with and without disabilities. When clubs were analyzed individually, the null hypothesis was rejected for only one club, Club 4. However, there were significant differences in a number of the indices, with Club 2 having differences in all indices, Club 3 showing differences in four indices and Clubs 1 and 4 having five differences in one index. The results were more dramatic however, when all clubs were combined and comparisons made. For example, there were statistically significant differences in all five indices on the survey tool when all the clubs were combined.

In summary, the results of this study support the premise that there were differences in perceptions among stakeholders in the organizations that participated in the research study. There appeared to be differences in perceptions between the leadership and the staff, between the leadership and the parents of children with and without disabilities, and between the staff and most of the parents. When leadership and staff are combined to represent the *organization* there were statistically significant differences between them and the *consumers*, who were parents of children without disabilities and parents of children with disabilities.

The findings support the hypothesis that in the organizations studied, the leadership (top management and board of directors) perceived that their organizations were further along the developmental continuum of inclusion, and also assumed that their existing business practices were in keeping with their mission statement and a commitment to diversity in general. The study also suggested that the full-time equivalent program staff did not share the same perception of how far along the developmental continuum the organization was, with the greatest differences being in how individuals with disabilities

were treated, how congruent the organization's espoused values were with their real practices, and what the motivational imperative of the leadership was to include individuals with disabilities. In addition, the study supported the findings that there was little or no difference in the perceptions between parents of children with and without disabilities in the organizations that had made a more formal commitment to inclusion, and for whom inclusion was more a way of doing business. And finally, when both groups (leadership and staff) were combined, their overall perceptions were that their organizations were further along a developmental continuum of inclusion that their consumers/ parents of children with and without disabilities believed.

CHAPTER 5

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Introduction

This study examined perceptions of stakeholders in youth development organizations who were engaged in the process of including individuals with disabilities. Specifically, this study focused on an organization that provides programs for children and youth, Boys & Girls Clubs, to see if there were differences in the perceptions of organizational stakeholders as to how far along a developmental continuum their organizations were in the change process. Earlier chapters introduced the reason for the study, examined the literature, described the methodology of data collection, and reported the findings specific to the four research questions.

This chapter will review and discuss those findings and make recommendations for future research, as well as implications for policy at both the macro and a micro level. The sample population for the study was 216 stakeholders from five Boys & Girls Clubs in San Diego County. Representatives from the clubs were asked to complete a survey called the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI – IWD)*, a tool developed by this researcher as an adaptation of a similar survey developed by Baron and Mitchell (1998), called the Organizational Developmental Model of Inclusion. The participants were asked to rate their level of agreement on a five point Likert Scale from strongly disagree to strongly agree, to statements that described specific conditions and characteristics of their organization. The research questions were designed to measure how far along the developmental continuum the organizations were, in regard to the level of inclusion of individuals with disabilities.

Mean scores for each of the five categories of the survey tool were computed and descriptive statistics and independent sample t-tests were used to test for differences between, and among, the stakeholder groups. The specific group comparisons related to the research questions and the details of analysis were reported in Chapter 4. This chapter contextualizes the results within the relevant literature.

The four groups of stakeholders identified for the study included 1) *Leadership* defined as the Executive Director, the Director of Operations, and the volunteer Board of Directors, 2) *Staff* defined as full-time equivalent program staff who have direct contact with children, youth and families, 3) *Parents of Children without Disabilities* (PCWOD) whose children were members of the club and participated in programs and activities, and 4) *Parents of Children with Disabilities* (PCWD) whose children were enrolled in the organization and also participated in programs and activities.

The following four research questions were used to measure the differences between, and among, the stakeholder groups:

- 1) How does each group of stakeholders rate their organization on the developmental continuum of inclusion?
- 2) What, if any, discrepancies exist between the perceptions of the agency's leadership, including the Board of Directors, the Executive Director and the Director of Operations and the full-time equivalent program staff, based on their rating of the organization on the developmental continuum of inclusion?
- 3) What, if any, discrepancies exist between the perceptions of parents of children without disabilities and the parents of children with disabilities based on their rating of the organization on the developmental continuum of inclusion?

4) What, if any, discrepancies exist between the perceptions of the organization, defined as leadership and program staff, and the perceptions of the consumers, defined as parents of children without disabilities and parents of children with disabilities, based on their rating of the organization on the developmental continuum of inclusion?

Discussion of Findings

Significant Differences Between and Among Stakeholders

The first research question was intended to determine how each group of stakeholders rated their organization on five different indices that reflected conditions and practices within the organization. The researcher's supposition was that if there were differences in the perceptions of the stakeholders as to how far along their organizations were in terms of inclusion, then it would support the fact that an organizational self reflection might be a useful tool in examining and adjusting their efforts to be more inclusive. Clearly, organizational culture cannot undergo change or reform without stakeholder voice and the valued relationships that evolve when those voices are heard. Fisher, Sax, Pumpian, Rodifer, and Kreikemeier (1997), described how, in the education model, shared leadership, commitment and communication positively impacted school's culture as related to the inclusion of students with disabilities. It seems reasonable that these values can be applied to other organizations with similar missions to support youth.

Organizational consultants understand that for change to be effective, the change process must be participatory (Arends & Arends, 1997; Krueger, 1988). Organizations describe positive outcomes when individuals in the process are empowered and they work together to define and describe issues and develop strategies for change (Bennis & Nanus, 1985; Blake & Mouton, 1981). Giving stakeholders a voice seems the logical start

to supporting a participatory process that will lead to collaboration among those stakeholders. Friend and Cook (1992), in an education model, define “interpersonal collaboration” as “a style for direct interaction between at least two coequal partners voluntarily engaged in shared decision making as they work toward a common goal” (p. 5). Again, an underlying premise of this study was that change would not occur, unless there was collaboration between stakeholders in designing, implementing and evaluating inclusion efforts throughout the process. The value of collaboration is consistently a theme in the business literature and is a central theme in educational reform in regard to restructuring regular and special education. Educators have examined and described a core set of values underlying collaborative relationships including parity, shared goals, and shared responsibility (Friend & Cook, 1992; Rainforth, York, & Macdonald, 1992; Thousand & Villa, 1992).

When the analysis was completed for research question one, there was an obvious difference in perceptions among all of the stakeholder groups. Results suggested that the leadership seemed to be somewhat out of touch with the perceptions of the staff, and also of the families of the children and youth that the agency served. The leadership in all five organizations consistently reported the highest scores, and rated their individual organizations further along a developmental continuum of inclusion than did the staff and the parents or children with and without disabilities.

This lack of congruency is a critical issue for several reasons – the first is that the leadership in these organizations is charged with several mandates, including a legal compliance issue under the Americans with Disabilities Act (ADA) to not discriminate against individuals with disabilities. The second critical issue is the importance of

recognizing the moral and ethical imperative to welcome and afford the same opportunities for participation to children with disabilities, as they do for the typically developing children that make up their membership. Executive staff and the Board of Directors bear responsibility for making fiscal decisions that support compliance with the ADA, and to support the staff that are charged with the day to day responsibility of welcoming, supporting and nurturing children and youth in the club.

In addition to the differences between leadership and staff, and leadership and families, there were also differences between staff and families in four of the five organizations as to how far along the developmental continuum their organizations were in terms of inclusion. This too, is a critical finding as it appears that the staff charged with implementing inclusive practices either lack awareness of what constitutes inclusion, perceive that their efforts are acceptable to the parents of the children they serve, or do not recognize the inherent value of partnering with families to ensure optimum outcomes for everyone.

The concept of partnering with families of children with disabilities has been well documented in the inclusive education literature. Bailey, et al (1998) in studies of exceptional children, confirmed that the importance of parent involvement is widely accepted, and it has been identified as a necessary, and valid, indicator of quality outcomes in the education of young children with disabilities. In addition, Bennet, DeLuca, & Bruns (1997) suggested that a school's underlying values about the education of children with disabilities influenced parent participation, and Soodak and Erwin (2000) documented that parent participation and collaboration is fostered by professionals and service providers who demonstrate interpersonal and communication skills that reflect

trust and respect. The same principle of respectful communication and collaboration between parents and staff applies to out-of-school time programs as well.

The second research question examined specifically the differences between the *leadership* and the full-time equivalent program *staff*. The results of the data analysis again confirm that there were significant differences in perceptions between the leadership and staff in three of the five indices on the survey tool; these differences were in the indices of *Differential Treatment*, *Congruency*, and *Motivational Imperative*. When differences such as these exist, the leadership must make a strong and unequivocal statement affirming their belief in the value of supporting inclusion. Kouzes and Posner (1993) suggested that the leadership must be verbally and physically overt and steadfast and unwavering in their communication regarding this new way of doing business. In describing the qualities of leaders they claimed, “Credibility is earned via the physical acts of shaking a hand, touching a shoulder, leaning forward to listen” (p. 46). When staff, families and visitors witness those acts of kindness and respect from leadership, they are more likely to believe that efforts to welcome individuals with disabilities are genuine, and internally rather than externally motivated. Then and only then, can the organization progress along a developmental continuum as they increase diversity, ensure their practices are congruent with their espoused values, and guarantee that individuals with disabilities are not treated differently in the organization.

If the staff that is interacting with children and families are not in agreement with what the leadership believes is occurring, the organization needs to reflect, make adjustments, and plan for change. Organizational change experts Tichy and Ulrich (1984) described ways to revitalize organizations and suggested four specific stages in organizational

transformation. They included: feeling a need to change, identifying and responding to stakeholders while creating a vision, mobilizing support and a commitment through dialogue, and modeling desired behaviors and attitudes. This transformational change can not occur, nor will it sustain itself, without an unwavering leadership that defines clear moral imperatives, encourages boundary crossing behaviors, and invites stakeholders, including individuals with disabilities or families of individuals with disabilities, as decision makers rather than passive recipients.

The third research question examined differences between the parents of children without disabilities and the parents of children with disabilities. There were little or no significant differences when all clubs were combined, however some differences were noted between the parent groups when clubs reported individually. For example, some parents of children without disabilities rated their organizations further on the developmental continuum, presumably because they saw children with disabilities physically represented in the club and considered that to be inclusion, when what they really observed may have been limited to the physical presence of children with disabilities.

The most significant difference between the parent groups was noted in one of the clubs where the parents of children with disabilities rated the club significantly further along the developmental continuum of inclusion than the parents of children without disabilities. This was an organization that had a long history of practicing inclusion and strong leadership early on in the process. That organization continues to have exceptional staff, has clearly embraced inclusion as demonstrated by its actions, has secured additional funding to support inclusion, truly celebrates differences in children,

and has received community recognition for having exemplary programs. Leadership, staff and parents of children with and without disabilities have been involved in and supported this new way of doing business and were driven by a moral imperative that it was “the right thing to do”.

The final research question examined differences between two redefined groups. First, everyone within the organization (staff and leadership including the volunteer board of directors) was called *organization*, and second, all parents of children (including those with and without disabilities) were called *consumers*. The null hypothesis was that there was no difference in the perceptions of the organization and the perceptions of the consumers as to how far along the developmental continuum the organization would be rated. When examined individually, the null hypothesis was rejected for four of the five clubs and when all clubs were combined and the sample size was larger, 107 for the organization and 109 for the consumers, the null hypothesis was again rejected as there were significant differences in all five indices. Clearly, the organization’s leadership and staff perceive that they are practicing inclusion, however, their perception of where the organization is developmentally in terms of inclusion is very different from what the consumers would like their children to experience. Physical presence alone does not constitute inclusion.

When such differences exist, there may be a disconnect between the persons responsible for designing and implementing programs and the beneficiaries of those programs. What the organization may consider to “be inclusion”, might in fact be symbolic inclusion, where the children are physically present but not participating in a meaningful manner, or perhaps the child is “included” only because he has a 1:1 aide,

which is just as segregating and/or isolating. Or perhaps the organization is supporting some segregated groupings, or keeping children with developmental disabilities with younger peers, which would likely not be the parental preference. If there is this type of disconnect between the organization and the families, there is likely a lack of communication and perhaps trust. Surely parents evaluate the organizational climate, underlying values, invitations and opportunities for parent involvement and a shared vision. They also look for support and trust from the organization's leadership when they evaluate inclusive environments and make decisions about their children's present and future lives. In addition, there are always families, perhaps because of education, culture, or experience, who do not know that they can expect more from community organizations or that they have a legal right to expect accommodations under the ADA.

Conclusions

This study showed that there were differences in perceptions between the stakeholders who participated in the study. Using descriptive statistics and independent sample t-tests, the study showed significant differences between stakeholders within organizations, and when the stakeholders from all organizations were combined, the differences between stakeholder groups became even more statistically significant. The most significant finding was that the leadership in all the organizations clearly felt their organizations were further along a developmental continuum of inclusion than the other three groups of stakeholders. If the leadership in an organization sees their goods and services, in this case programs, through a different lens than the staff of the organization, or the consumers who purchase the services, it suggests that the organization has considerable adaptive work to do if there are to become truly inclusive.

Organizations that have begun to include individuals with disabilities are engaged in a process that is transforming the way they do business as they invite a whole new group of customers to join their organizations. Some of them begin the process of including individuals with disabilities because of a legal mandate and/or because of the threat of a lawsuit, while others begin the process because there may be an opportunity to receive additional funding or access resources, addressed in this study as *motivational imperative*. The study also examined whether or not the organizations' policies and procedures were reflective of their mission statement by measuring *congruency* between their espoused values and actual practices. Finally the study examined the realities of individuals with disabilities in the organization. i.e., how they were represented in real numbers (*diversity*), how they were treated (*differential treatment*) and what their real experience felt like (*experience of the minority*).

The results of the study reinforced the impressions and experiences of the researcher. Having spent 30 years working with individuals with disabilities and their families, including the last 10 years exclusively with out-of-school time programs for children and youth, this researcher is interested in how organizations move along a developmental continuum of providing services to children with disabilities and other special needs. The study verifies that, in fact, even among organizations that are practicing inclusion in their out-of-school time programs, there is almost always a misalignment of perceptions between the leadership and the staff, between the staff and the parents, and between the organization and the consumers. In addition, there appears to be a lack of strategic planning, and typically no means of evaluating how they are doing organizationally in providing respectful, inclusive experiences for children with disabilities and their

families.

Judith Katz (1989) described how developmental phases are key elements in an organization's shift toward "multiculturalism" and she recommended that the process include addressing issues of discrimination and diversity. The results of this study and professional experience support the premise that there are, in fact, clearly defined developmental phases in organizations as they adapt and shape their culture to increase meaningful representation of individuals with disabilities. A further premise is that before an organization implements inclusive practices, they must begin with organizational and individual self- reflections.

These reflections are a form of cultural audit and can assure that the organization's membership examines both individual and organizational biases and stereotypes, reflects on their own fears and experiences, and feels safe in sharing whether or not they recognize the existence of a social injustice within the organization. Bellah, Madsen, Sullivan, Swindler, & Tipton (1985) remind us that "at the core of any viable institution there is a moral code which must be periodically reinvigorated so that the institution may survive and flourish (p. 41). Only after that organizational audit/self reflection, can the organization and its members commit to change, knowing that they have considerable adaptive work to do to move toward creating inclusive communities.

Using a Developmental Continuum to Measure Organizational Change

References to developmental phases in facilitating organizational change are extensively documented in the business literature. For example, Tichy and Ulrich (1986) describe four distinct phases and management techniques that are necessary to revitalize organizations. The first phase they describe is the *Need to Change* – when the

organization recognizes dissatisfaction with the status quo as a result of first identifying and then being receptive to stakeholder voices. The next phase is *Creation of a Vision* – a period of time when the vision is articulated and supported by the leader’s philosophy and style. The third phase is *Mobilizing of Commitment* – a process that involves significant dialogue and exchange, at the same time that the leadership models behaviors and attitudes that reflect the shared vision. The final developmental phase is *Institutionalization* – perhaps the greatest challenge and one they suggest requires transformational leadership, as the organization shapes and reinforces a new culture.

The business literature, specifically the studies that examined organization change, set the stage for using a similar developmental continuum model of change for this research study. Recognizing that a developmental process involves stages of change, and that the stages occur in a logical and thoughtful sequence, the theory supports this study and suggests that when considerable adaptive work is required, a logical place to start is with an organizational self-reflection. The change process can not begin until all the stakeholders are given a voice, and those voices must continue to be heard as the organization begins to implement and design a new line of services and products, in this case inclusive programming.

While the business literature had many references to organizational change as a developmental process, the only literature that referred to a developmental continuum for organizations that are including individuals with disabilities, was a model described in the recreation literature by Schleine, Green and Stone (1999). In this model, they define the inclusion continuum as having three levels of acceptance. The first stage they describe is purely *physical integration*, which came as result of legislative mandates. The

second level or stage is called *functional inclusion*, a time and place when the individual with disability clearly has the ability to function within the environment, and that stage implies that the staff has adequate knowledge and resources to support inclusion. The third and final stage in their continuum is *social inclusion*, which cannot be mandated, but must be internally motivated. At this stage, the individual with disability gains social acceptance and/or participates in positive interactions with peers during recreation activities. This is a stage that occurs when an organization truly embraces inclusion as a value.

The recreation model is consistent with the researcher's model that was composed of four stages – Exclusion, Symbolic Inclusion, Supported Inclusion and Inclusion. The specific number of stages and their labels is not nearly as important as the recognition of inclusion as a process. Organizations need to know where they are in the process in order to begin to change the way they do business and to transform the very culture of their organizations.

Policy Implications

Macro System Implications

There are 48.9 million non-institutionalized Americans with disabilities over the age of 5 years (U.S Census, 2000), yet in the twenty-first century, the majority of individuals with disabilities continue to encounter social, psychological and economic barriers while they strive for respect, empowerment and inclusion in their communities. While there has been some improvement in the quality of their lives in recent decades, most individuals with disabilities continue to experience few opportunities for meaningful inclusion and many continue to live in relative isolation (Disability Abstract, 1998).

The dismal outcomes for adults with disabilities who have primarily been served in segregated and very time-limited programs, clearly suggest that legislation alone does not create systems change. There are no “ADA Police” who are enforcing compliance with the Americans with Disabilities Act. Some adults and some children have experienced successful inclusion in their communities however, their presence is typically a result of tremendous advocacy and tenacity and resiliency by their families and/or themselves. Unfortunately, few families have the resources and energy to challenge the systems and the barriers that have distanced their children from their communities. There is a clear moral imperative to support systems change, both in policy and in organizational culture that might change the future for the over 2.6 million children in this country who have one or more disabilities (U.S. Census, 2000). They deserve the right to brighter futures than adults with disabilities, who before them, have had limited or no access to recreation, leisure activities or child care, or when it was available to them, it was frequently time limited and segregated. Segregated programs, while meeting a need for many individuals with disabilities, have had an impact of supporting disenfranchisement and distancing those individuals from their natural communities (Condeluci, 1995). These children deserve a right to experience “belonging” and meaningful participation in their communities, just as every other child in America.

The cultural change that precedes systems change will not occur without a paradigm shift in how society views disability. The concept of a paradigm suggests a set of rules and regulations that defines boundaries and that tells you what to do to be successful within those boundaries. In this case, the earlier paradigm - a medical model - was based on a deficit model where experts were in charge and goals were determined without the

individual with disability's voice. The result was a system that segregated individuals and contributed to isolation and dependence. The new paradigm is an empowerment model that fosters interdependence, focuses on capacities, values relationships, is driven by the consumer, and promotes micro/macro changes (Condeluci, 1995). The empowerment paradigm supports a model that suggests that rather than suppressing differences, we should honor them and build a commonality between us. Tierney (1992) defines the challenge as follows: "We are often told to build community in our institutions, but we are left with a feeling that we neither have the fiscal nor moral tools to do so" (p.16).

Leadership is critical to facilitate the kind of organizational change that will influence policy and practice. People in positions of power and influence at national, regional and local levels have the ability to lead, direct and facilitate changes that will result in institutions and systems that welcome and support diversity, while correcting a social injustice. While there has been significant change in recent decades in institutions and society in addressing diversity issues in race, ethnicity, gender, and sexual orientation, there has been less progress in addressing issues of equity and opportunity for individuals with disabilities. Theologian and philosopher Paul Ricoeuer (1992) reminds us it is not enough to think about ethics and social justice, but that we must act to "create the 'good life' with and for others in just institutions"(p. 172).

While the system needs to change at all levels, a hopeful sign is that in some educational settings in more progressive states and districts, there have been dramatic changes in how children with disabilities are educated. School districts have demonstrated that with strong leadership, participatory decision making, and collaboration, children with disabilities can be and are included, and the benefits for those

children as well as the typically developing children and the entire school community are evident. While there are reasons to celebrate the gains in education, unfortunately there are fewer examples of emerging change or leadership in the landscape for children with disabilities during out-of-school time hours. As more and more parents have entered the work force in the last decade, child care issues have increasingly demanded attention from policy makers and organizations that fund child care initiatives. However, only very recently, have those policy makers addressed children with disabilities and the only system they have addressed, as in early childhood care (birth to five years). As a result, a noticeable void exists in child care policy when it comes to school age children, and the void is even more dramatic for teenagers with disabilities, whose families continue to need child care. This study is particularly interested in influencing policy for out-of-school time programs at the national, state and local level.

For the last several years, 21st Century Community Learning Centers, most located on elementary and middle school campuses and funded by the U.S Department of Education, have proliferated as a result of *No Child Left Behind*, and schools and communities have become more involved and responsive to children in out-of-school time hours. As programs have expanded, so have professional associations that support school age issues. Those organizations include the National Afterschool Association (NAA), the Afterschool Alliance, the Finance Project, and the National Institute for Out-of-School Time (NIOST), as well as many similar organizations at state levels. Additional partners include organizations that provide major funding support for after school initiatives, i.e., the Charles Stewart Mott Foundation and J.C Penny.

While hundreds of thousands of children and youth attend out-of-school time

programs in their communities, there are very few opportunities for children with disabilities to attend the same programs. Since more than seven percent of boys and four percent of girls between the ages of 5 and 15 years are identified as having at least one disability (U.S. Census 2000), these organizations need to ensure these children are included in their initiatives. In addition, organizations that provide accreditation to programs with the intention of improving quality, and professional associations that plan national and regional conferences for youth development professionals, need to ensure that the topic of including children with disabilities is offered in general sessions and not only as optional break-out sessions. While the legal mandate that prohibits discrimination against individuals with disabilities has not resulted in systems change, professionals who support children, youth and families must recognize the need to change a system that directly and indirectly condones a social injustice that excludes or symbolically includes an entire class of children in this country.

Micro System Implications for Out-of-School Time Programs

While systems change is required in policies and practices at the macro level, there is also a legal and ethical mandate to change at a micro level, including every corporate or not for profit organization that supports children, youth and families in our communities. One only needs to ask parents of children with disabilities what is missing in their child's life to recognize that all families want to have places in their communities outside of school walls, where their child can go: where they are welcome and safe; where they can learn new things; develop skills and interests; grow emotionally into socially competent people; be surrounded by caring, respectful adults; and develop friendships with other children. Unfortunately, there continue to be few opportunities for children with

disabilities to experience inclusion during out-of-school time hours.

This research study was based on the fact that the creation and maintenance of a culturally inclusive institution is a developmental process. In order to design, implement and sustain inclusive practices, it is necessary to develop a strategic plan for change. Before that plan can be developed, however, there must be recognition that change is required and the organizations must identify the internal and external motivators that can facilitate that change. The organizations at the micro level that must embrace the change include the Boys & Girls Clubs, the YMCAs, Park and Recreation programs, before and after school programs on school campuses, enrichment programs, scouting, 4-H, and similar organizations that serve children and youth.

All organizations and institutions have a culture, a starting point, and a history defined by philosophy and mission, and generally driven by values, norms and practices. When an organization's culture endorses or allows discrimination, and ignores the existence of a social injustice, the leadership must draw attention to the injustice, invite stakeholder voices, begin organizational self-reflections, communicate a clear vision and develop a strategic plan to celebrate diversity. Leadership is the single most important ingredient for the transformational change that is required of organizations that embrace inclusion. Heifetz (1994) offers a call for "getting on the balcony" to identify internal conflicts or problem dynamics (p.258). He also suggested that leadership is both active and reflective, and that the leader must manage the adaptive challenges involved in changing the dynamics of a social system that allows or condones a social injustice. This implies not an affirmative action approach, but an affirming diversity approach.

Part of the organizational self-reflection involves examining the mission statement and

ensuring that it is not empty words, but a statement that is defined by daily acts and practices. This is the time to commit to broad stakeholder representation, so that a multitude of voices can assist in designing, implementing and evaluating the process of welcoming and supporting the inclusion of individuals with disabilities. Burns (1978), in discussing transformational leadership described a model of mutual goals as when “one or more persons engage with *others* in such a way that leaders and followers raise one another to higher levels of motivation and morality” (p. 20).

A major challenge for the leadership is to keep the right people in the right places and to continue to identify change agents, those who may be defined as “moral compasses” who will continue to ensure that the attention of the organization is kept on the adaptive challenge. There must also be support for boundary crossers, those who leave the confines of the organization to collaborate, find resources and natural supports that will ensure sustainability and quality, and who will not allow the organization to be dependent on any one person or group of persons. Transformational leadership can and will support the process of inclusion and the result will be the creation of caring communities.

Recommendations for Future Research

Several recommendations for future research are included. A very specific recommendation by this researcher is to revise the *Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI)* survey tool by shortening it to five or six statements in each of the five categories, thereby making it a 25 or 30 item survey, more manageable and yet still able to capture the essence of the process. Once the tool is revised, further studies could be conducted across many systems of support for children in out-of-school time programs.

Another recommendation is to conduct quantitative studies that would measure outcomes for children, with and without disabilities, when they are included in the same programs and supported by respectful, trained, adult care providers who understand the value of inclusion. While measures that describe gains in academic and social skills would be clearly important for children with disabilities, measures of character education and the development of empathy in children without disabilities should also be included. Ideally, the outcomes measures for children and youth with disabilities in longitudinal studies should measure examples of interdependence including number and quality of relationships, reciprocity in friendships, expanding natural opportunities to connect with others, development of new skills or interests, and overall quality of life issues and connections into adulthood for these children.

In addition, researchers are urged to continue to examine differences in the expectations and responses of families who represent different cultures or socio-economic conditions. Although studies are limited, the literature suggests that there are likely differences in cultural norms in terms of what families expect from providers. The issue of encouraging parent voice and empowering them to become stakeholders in the inclusion process must be addressed and evaluated. On the other end of the spectrum, Gravidia-Payne and Stoneman (1997) suggested that parents were more likely to be involved when they had greater financial resources and education, effective coping strategies, and access to social support. Understanding the differences and how to empower parents with fewer resources and less education, or for whom English is a second language, would be clearly helpful in the long term both for their children and themselves.

A final recommendation for future research is to quantitatively measure changes in the cultural climate of out-of-school time programs that have included children with and without disabilities. Many of these programs now have formal “anti-bullying” curricula and the current theory supports the notion that children have to be taught “tolerance” which seems to be based on a theory of dividing up dimensions of being human. By valuing diversity and creating truly inclusive environments that celebrate differences, rather than managing diversity, we can begin to witness a culture change within our schools and after school communities. Arredondo (1996) emphasized that when organizations develop a humanistic culture, they convey a message of value. Children are born without stereotypes and biases, yet we know that they can develop them quickly, and those biases will never disappear. If however, they are given opportunities to experience diversity, and if the adults in the environment model respect for differences, and have a clear moral imperative that inclusion is indeed “the right thing to do” then we will, in fact, create caring communities in our life time and future generations of children will inherit a world where ALL people are valued.

The first line in this research study began with a quote from a book called *Circle of Friends*. We long for wisdom to make the world more decent and tolerable and caring, a world where all of us figure in one another’s survival. We believe that much of the wisdom needed for the task comes from reaching toward those we may have been programmed to avoid (Perske & Perske, 1988). It seems fitting that the last line in the study should reflect a hope for children with disabilities and their families. Graham Greene (1996) captured that sentiment when he wrote that there is always one moment in a child’s life when the door opens and lets the future in. We have a shared responsibility

to open the doors in every institution that supports children and youth, and literally let the future in for the hundreds of thousands of children and youth with disabilities in this country.

REFERENCES

- Adler, N. (1991). *International Dimensions of Organizational Behavior*. Boston: PWS – Kent Publishing Company.
- Ambrose, D. (1987). *Managing Complex Change*. Pittsburg, PA: The Enterprise Group, Ltd.
- Andreasen, A.R. (1995). *Marketing social change: changing behavior to promote health, social development, and the environment*. San Francisco: Jossey-Bass.
- Arends, R. I., & Arends, J. H. (1997). *Systems change strategies in educational settings*. New York: Human Sciences Press.
- Arredondo, P. (1996) *Successful Diversity Management Initiatives: A blueprint for planning and implementation*. Thousand Oaks: Sage Publications
- Ayres, B., Meyer, L., Erevelles, N., & Park-Lee, S. (1994). Easy for you to say: Teacher perspectives on implementing most promising practices. *The Journal of the Association for Persons with Severe Handicaps*, 19,(2), 84-93.
- Bailey, D. B., McWilliam, R. A., Darkes, L. A., Hebbeler, K., Simeonsson, R. J., Spiker, D., & Wagner, M. (1998). Family outcomes in early intervention: A framework for program evaluation and efficacy research. *Exceptional Children*, 64, 313-328.
- Baron, M., & Mitchell, M. A., (1998). *Organizational developmental model of inclusion*. San Diego: Authors.
- Bassoff, B., & Shea, M. (2000). *San Diego Childcare and Development Committee Report*, San Diego County Commission on Children and Youth, San Diego, CA.

- Beckhard, R., & Harris, R.T. (1987). *Transitions: Managing complex change*. (2nd ed.). Reading, MA: Addison-Wesley.
- Bellah, R.N., Madsen, R., Sullivan, W. M., Swindler, A., & Tipton, S.M. (1985). *Habits of the heart*. New York: Harper and Row.
- Bennet, T., DeLuca, D., & Bruns, D. (1997). Putting inclusion into practice: Perspectives of teachers and parents. *Exceptional Children*, 64, 1125-131.
- Bennis, W., & Nanus, B. (1985). *Leaders: The strategies for taking charge*. New York: Harper and Row.
- Bennis, W. (1989). *On becoming a leader*. New York: Addison-Wesley.
- Bennis, W. (1993). *An invented life: Reflections on leadership and change*. Reading, MA: Addison – Wesley.
- Blake, R. R., & Mouton, J. S. (1981). *Productivity: The human side*. New York: AMACOM.
- Borg, W. R., & Gall, J.C. (1983). *Educational research: An introduction*. White Plains, NY: Longman Publishers.
- Brown v Board of Education, 347 U.S. 483 (1954).
- Burns, J. M. (1978). *Leadership*. New York: Harper and Row.
- Burns, J. M. (1989). *The Crossroads of freedom*. New York: Random House
- California Map to Inclusive Child Care Project (2000). *Barriers to child care in California for children with disabilities and other special needs*. Sacramento, CA: California Department of Education.

- Carrell, M., & Mann, E. (1995). Defining workforce diversity in public-sector organizations. *Public Personnel Management* 2 (1), 99-111.
- Clark, K.E., & Clark, M. B. (1994). *Choosing to lead*. Charlotte, NC: Iron Gate Press.
- Coleman, J.C. (1972). *Abnormal psychology and modern life* (4th ed.). Glenview, IL: Scott Foresman.
- Condeluci, A. (1995). *Interdependence: The Route to Community*. Boca Raton, FL: CRC Press
- Connor, D. R. (1993). *Managing at the speed of change*. New York: Villard.
- Copeland, L. (1988). Making the most of cultural differences in the workplace. *Personnel* 65 (6), 52-60.
- Cordeiro, P., & Monroe-Kolek, M. (1996). Introduction: Connecting school communities through educational partnerships. *New Directions for School Leadership* 2, 1-14.
- Covey, Stephen (1989). *The 7 habits of highly effective people*. New York: Simon and Shuster.
- Cox, F. M. (1974). A suggestive schema for community problem solving. In F.M. Cox, J.L. Erlich, J. Rothman, & J. F. Tropman (Eds.), *Strategies of community development: A book of readings*. (pp. 425-429). Itasca, Illinois F. F. Peacock.
- Cox, F. M. (1974). Comments on a suggestive schema for community problem solving. In F.M. Cox, J.L. Erlich, J. Rothman, & J. F. Tropman (Eds.), *Strategies of community development: A book of readings*. (pp. 430-444). Itasca, Illinois F. F. Peacock.

- Cox, T. (1993). *Cultural Diversity in Organizations: Theory, research and practice*. San Francisco: Barrett-Koehler Publishers.
- Darling, R. (1988). Parental Entrepreneurship: A consumerist response to professional dominance, *Journal of Social Issues*, 44 (1), 141-158.
- Deal, T. (1987). The culture of schools. Leadership: Examining the elusive. In Shieve, L., & Schoenheit, M. (Eds.), *Association for Supervision and Curriculum Development*, Alexandria, VA.
- Deal, T., & Peterson, K. (1990). *The principal's role in shaping school culture*. Washington, D.C: U.S. Government Printing Office.
- Deming, W.E. (1986). *Out of the crisis*. Cambridge, MA: MIT Center for Advanced Engineering Study.
- DePree, M. (1992). *Leadership Jazz*. New York: Doubleday.
- Devillis, R. F. (1991). *Scale development: Theory and applications*: Newbury Park, CA: Sage.
- Disability Statistics Program, (1998). *Disability Statistics Abstract*. San Francisco: Institute for Health and Aging, University of California.
- Dunn, W., & Swierczek, F. (1977). Planned organizational change: Toward grounded theory. *Journal of Applied Behavioral Science*, 13(2), 135-157.
- Falvey, M. (1995). *Inclusive and heterogenous schooling: Assessment, curriculum and Instruction*. Baltimore: Paul H. Brookes Publishing Co.

- Federal Interagency Forum on Child and Family Statistics (1999). *America's Children: Key National Indicators of Well-Being, 1999*. Washington, D.C: U.S. Government Printing Office.
- Finch, F. E. (1977). Collaborative leadership in work settings. *Journal of Applied Behavioral Science*, 13 (3), 292-302.
- Fink, A. & Kosecoff, J. (1998). *How to conduct surveys: A step by step guide* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Finn, C.E., (1990). The biggest reform of all. *Phi Delta Kappan*, 71, 582-592.
- Fisher, D., Sax, C., Pumpian, I., Rodifer, K., & Kreikemeier (1997). Including all students in the high school reform agenda. *Education and Treatment of Children* (20), No. 1.
- Forest, M. (1988). Full inclusion is possible. *IMPACT*, (1), 3-4.
- Foster, W. (1989). Toward a critical practice of leadership. In Smyth, J. (Ed.), *Critical perspectives in educational leadership*. (pp. 39-62). London: Falmer Press.
- Friend, M. & Cook, L. (1992). *Interactions: Collaboration skills for school professionals*. White Plains, NY: Longman.
- Gilhool, T. (1989). The right to an effective education: From Brown to P.L. 94-142 and beyond. In D. K. Lipsky & A. Gartner (Eds.), *Beyond separate education. Quality education for all* (pp. 43-253). Baltimore: Paul H. Brookes.
- Gold, M. (1980). *Try another way: Training manual*. Champaign, IL: Research Press.

Gravidia-Payne, S., & Stoneman, Z. (1997). Family predictors of maternal and paternal involvement in programs for young children with disabilities. *Child Development*, 68, 701-717.

Greene, Graham (1996).

http://www.brainyquote.com/quotes/authors/g/graham_greene.html

Gudykunst, W.B. (1994). *Bridging differences: Effective intergroup communication*. Thousand Oaks, CA: Sage Publications.

Harris, L. and Associates, Poll of Americans with Disabilities (1998). *National Organization on Disability*. Washington, D.C.

Harris, L. and Associates, Poll of Americans with Disabilities (2000). *National Organization on Disability*. Washington, D.C.

Harris, L. & Associates, Poll of Americans with Disabilities (2004). *National Organization on Disability*. Washington, D.C.

Helgeson, S. (1990). *The female advantage: Women's ways of leadership*. New York: Doubleday.

Heifetz, R.A. (1994). *Leadership without easy answers*. Cambridge, MA: Harvard University Press.

Hewett, F. M., & Forness, S. R. (1984). *Education of exceptional learners*. (3rd. ed.). Boston, MA: Allyn and Bacon.

Kanter, R. (1977). *Men and women of the corporation*. New York: Basic.

Kanter, R. M. (1983). *The change masters*. New York: Simon & Shuster.

- Kanter, R. M., Stein, B.A., & Jick, T.D. (1992). *The challenge of organizational change: How companies experience it and leaders guide it*. New York: McGraw-Hill.
- Katz, J. (1998). The challenge of diversity. In Woolbright, C. (Ed.), *Valuing diversity on campus: A multicultural approach*. Association of Colleges.
- Kettner, P. M., Daley, J. M., & Nichols, A.W. (1985). *Initiating Change in Organizations and Communities*. Monterey, CA: Brooks/Cole.
- Kotter, J. P. (1990). *A force for change: How leadership differs from management*. New York: The Free Press.
- Kouzes, J. M., & Posner, B. Z. (1993). The credibility factor: What people expect of leaders. In Rosenbach, W.E., & Taylor, R. (Eds.), *Contemporary issues in leadership*. (pp. 57- 61). Boulder, CO: Westview Press.
- Knostner, T. (1991). Personal communication. December 4, 1991.
- Krueger, R.A. (1988). *Focus Groups: A practical guide for applied research*. Newbury Park, CA: Sage Publications.
- Lamorey, S., & Bricker, D.D.(1993). Integrated programs: Effects on young children and their parents. In C.A. Peck, S.L. Odom, and D. D. Bricker, (Eds.), *Integrating young children with disabilities into community programs: Ecological perspective on research and implementation* (pp. 249). Baltimore, MD: Paul H. Brookes Publishing.
- Larkin, T. J., & Larkin, S. (1994). *Communicating Change*. New York: McGraw-Hill.
- Lewin, K. (1951). *Field theory in social science*. New York: Harper & Row.
- Likert, R. (1932). A technique for measurement of attitudes. *Archives of Psychology*

- Lippett, R., Watson, J., & Wesley, B. (1958) *The Dynamics of Planned Change*. New York: Harcourt, Brace and World.
- Littrel, C., Billingsley, B.S., & Cross, L. H. (1994). The effects of principal support on special and general educators' stress, job satisfaction, school commitment, health, and intent to stay in teaching. *Remedial and Special Education* 15, 297-310.
- Loden, M., & Rosner, J. (1991). *Workforce American: Managing diversity as vital resource*. Homewood, IL: Business One Irwin.
- Lyon, G.R., Vaassen, M., & Toomey, F. (1989). Teachers' perceptions of their undergraduate and graduate preparation. *Teacher Education and Special Education* 12, 4: 164-169.
- McKnight, J. (1987). Regenerating Communities. *Social Policy*, Winter Issue.
- Morrison, J., and Ursprung, A. (1987). Children's attitudes toward people with disabilities: A review of the literature. *Journal of Rehabilitation*.
- Mount & Zwernick, (1987). *It's never too early. It's never too late*. St. Paul, MN: Metropolitan Council.
- Nadler, D.A. (1981). Managing organizational change: An integrative perspective. *Journal of Applied Behavioral Science* 17 (2) pg. 191-211.
- National Association of State Boards of Education (NASBE). (1995). *Winning ways: Creating inclusive schools, classrooms, and communities* (Report of the NASBE Study Group on Special Education). Washington, D.C.

- National Commission on Excellence in Education.(1983). *A nation at risk*. Washington, DC: United States Department of Education.
- O'Brien, J. (1986). *Discovering Community*. Atlanta, GA: Responsive Systems Associates.
- Odiome, G.S. (1967). *The human side of management*. Lexington, MA: D.C. Heath.
- Odom, S.L., & Brown, W.H. (1993). Social interaction skills intervention for young children with disabilities in integrated settings. In C.A. Peck, S.L. Odom, and D.D. Bricker (Eds.), *Integrating young children with disabilities into community programs: Ecological perspective on research and implementation* (pp. 3-15). Baltimore, MD: Paul H. Brookes Publishing.
- Parham, T. & Parham, W. (1995). *Institutionalizing Cultural Diversity: A follow-up assessment on the outcomes of the Irvine Foundation Grant at the University of San Diego*. San Diego, CA.
- Parnes, S.J. (1988). *Visionizing: State-of-the-art processes for encouraging innovative excellence*. East Aurora, NY: D.O.K.
- Patton, M. Q. (1982). *Practical evaluation*. Beverly Hills: Sage Publications
- Perske, R., & Perske, M. (1988). *Circles of Friends: People with disabilities and their friends enrich the lives of one another*. Nashville, TN: Abingdon Press.
- Peters, T. & Waterman, R.H. (1982). *In search of excellence*. New York: Harper & Row.
- Pfeffer, J. (1992). *Managing with power: Politics and influence in organizations*. Boston: Harvard Business School Press.

- Pinderhughes, J. (1989). *Understanding race, ethnicity, and power: The key to efficacy in clinical practice*. New York: Free Press.
- Porter, L.W. & McKibbin, L. E. (1988). *Management education and development: Drift or thrust into the 21st Century?* New York: McGraw-Hill.
- Plunkett, L.C. & Fournier, R. (1991). *Participative management: Implementing empowerment*. New York: John Wiley & Sons.
- Public Law 88-156: *The Maternal and Child Health and Mental Retardation Planning Amendments of 1963*. Washington, D.C.
- Public Law 88-164: *The Mental Retardation Facilities and Community Mental Health Centers Construction Act* (1962). Washington, D.C.
- Public Law, 91-517: *The Developmental Disabilities Services and Facilities Construction Act* (1970). Washington, D.C.
- Public Law, 93-112: *The Rehabilitation Act* (1973). Washington, D.C.
- Public Law 94-142: *The Education for All Handicapped Children Act* (1975). Washington, D.C.
- Public Law 94-103: *The Developmental Disabilities Assistance and Bills of Rights Act* (1975). Washington, D.C.
- Public Law 99-457: *The Education for All Handicapped Children Act Amendments of 1983*. Washington, D.C.
- Public Law 99-457: *The Education for All Handicapped Children Act Amendments of 1986*. Washington, D.C.

- Public Law 101-476: *The Individuals with Disabilities Education Act* (1990).
Washington, D.C.
- Public Law 101-336: *The Americans with Disabilities Act* (1990). Washington, D.C.
- Rainforth, B., York, J., & Macdonald, C. (1992). *Collaborative teaming to support the education of students with severe disabilities*. Baltimore: Paul H. Brookes.
- Raison, J., Hanson, L., Hall, C., & Reynolds, M.C. (1995). Another school's reality. *Phi Delta Kappan*, 76, 480-482.
- Riceouer, P. (1992). *Oneself as Another*. Chicago, IL: University of Chicago Press.
- Rost, J.C. (1991) *Leadership for the twenty-first century*. New York: Praeger.
- Sarason, S. (1990). *The predictable failure of school reform: Can we change course before it's too late?* San Francisco: Jossey-Bass.
- Sashkin, M., & Egermeier,, J. (1993). *School change models and processes: A review and synthesis of research and practice*. Washington, D.C: U.S. Department of Education.
- Schaffer, R. H., & Thomson, H.A. (1992). Successful change programs begin with results. *Harvard Business Review* (Jan – Feb), 80 – 89.
- Schlechty, P. (1990). *Schools for the 21st century: Leadership imperatives for educational reform*. San Francisco: Jossey-Bass.
- Schleine, S., Green, F., & Stone, C. (1999). Making friends within inclusive recreation programs. *Journal of Leisurability*, 26 (23).
- Senge, P. (1990). *The fifth discipline*. New York: Bantam Doubleday Bell.
- Sergiovanni, T. J. (1990). *Value added leadership: How to get extraordinary performance in schools*. Orlando, FL: Harcourt Brace Jovanovich.

- Shakeshaft, C. (1987). *Women in educational administration*. Newbury Park, CA: Sage.
- Sims, R., & Dennehy, R. (1993). *Diversity and differences in organizations: An agenda for answers and questions*. Westport, CT: Quorum Books.
- Skrtic, T. M. (1991). The special education paradox: Equity as the way to excellence. *Harvard Educational Review*, 61(2), 148-206.
- Sloan, E.S. (1995). "In the name of the child: An exploratory multi-case study of collaborative interactions in elementary school-based health centers in Connecticut." Unpublished doctoral dissertation, the University of Connecticut.
- Smith, T. (1993). *Parzival's briefcase*. San Francisco: Chronicle Books.
- Smith, A. (1997). Systemic education reform and school inclusion: A view from a Washington office window. *Education and Treatment of Children*, (20), 7-20.
- Soodak, L.C. & Erwin, E. J. (2000). Valued member or tolerated participant: Parents' experience in inclusive early childhood settings. *The Journal of the Association for Persons with Severe Handicaps*, 25 (1), 29-41.
- Soni, V. (2000). A twenty-first century reception for diversity in the public sector: A case study. *Public Administration Review*, 60, (5).
- Sower, C., Holland, J., Tredke, J., & Freeman, W. (1957). *Community Involvement*. Glencoe, IL: The Free Press.
- Staub, D., Spaulding, M., Peck, C.A., Galluci, C. & Schwartz, I.S. (1996). Using nondisabled peers to support the inclusion of students with disabilities at the junior high school level. *The Journal of the Association for Persons with Severe Handicaps*, 21, 194-205.

Sue, D. W. and Sue, D. (1990). *Counseling the culturally different* (2nd ed.). New York:

John Wiley.

Survey Monkey (2005) <http://www.surveymonkey.com>

Taylor, S. J., Biklen, D., & Knoll, J.(1987). *Community integration for people*

with severe disabilities. New York: Teachers College Press.

Terry, R. W. (1993). *Authentic Leadership*. San Francisco: Jossey-Bass

Thomas, R. (1991). *Beyond Race and Gender*. New York: American Management

Association.

Thousand, J. S., & Villa, R. (1992). Collaborative teams: A powerful tool in school

restructuring. In R.A. Villa, J.S. Thousand, W. Stainback & S. Stainback (Eds.),

Restructuring for caring and effective education: An administrator's guide to creating

heterogenous schools (pp. 73–108). Baltimore: Paul H. Brookes Publishing Co.

Thousand, J. S. & Villa, R. A. (1995). Managing complex change toward inclusive

schooling. In R.A. Villa & J.S. Thousand (Eds.), *Creating an inclusive school*

(pp.51-79). Alexandria, VA: Association for Supervision and Curriculum

Development.

Tichy, N. M., and Devanna, M.A. (1986). *The transformational leader*. New York:

Wiley.

Tichy, N. M., and Ulrich, D. (1984). Revitalizing organizations: The leadership role. In

J. Kimberly and R. Quinn (Eds.), *New futures: The challenge of managing corporate*

transitions. Homewood, IL: Dow Jones - Irwin.

- Tierney, W.G. (1992). Cultural leadership and the search for community. *Liberal Education* 78 (5), 16 -21.
- Toffler, A. (1970). *Future shock*. London: The Bodley Head.
- United States Census Bureau (2000).
- Vandercook, T., & York, J. (1990). A team approach to program development and support. In W. Stainback & S. Stainback (Eds.), *Support networks for inclusive schools*. Baltimore: Paul H. Brookes.
- VanDyke, R., Stallings, & Colley, K. (1995). How to build an inclusive school community: A success story. *Phi Delta Kappan*, 76, 475-479.
- Walton, M. (1990). *Deming management at work*. New York: Perigree.
- Wang, M.C., Reynolds, M.C., & Walberg, H.J. (1988). *Handbook of special education research and practice: Mildly handicapped conditions*. New York: Pergamon.
- Warren, R. (1978). *The Community in America*. (3rd ed.). Chicago: Rand McNally College Publishing Co.
- Webster (1973). *New World Dictionary*. New York: Simon and Shuster
- Wolfensberger, W. (1972). *The Principle of Normalization in Human Services*. Toronto, Ont: National Institute on Mental Retardation.
- Work, J. W. (1996). Leading a diverse workforce. In Hasslebein, F., Goldsmith, M. & Taylor, R. (Eds.), *Contemporary Issues in Leadership*. (pp. 36-56). Boulder: CO: Westview Press.
- Yatvin, J. (1995). Flawed assumptions. *Phi Delta Kappan*, 76, (6), 482-484.
- Zikmund, W. G. (1991). *Business research methods*. (2nd ed.). Chicago: Dryden Press.

Appendix A

Letter of Introduction and Request for Support of Dissertation

Date

Salutation:

Dear _____

I am writing to you at this time as a follow up to the email communication and/or verbal conversation I have had with you in the recent past regarding my doctoral dissertation. While you may know me in the capacity of Executive Director of Kids Included Together (KIT), or more recently as Director of Site Development at KIT, I am writing this request to you as an individual with no affiliation to Kids Included Together but rather as a doctoral student in the School of Education at the University of San Diego. I am in the final stages of completing a dissertation so that I may graduate in spring 2005. I am conducting this research under the direction of Dr. Fred Galloway in the School of Education at USD.

I have spent my entire professional career (over 30 years) working with children with disabilities and their families and the last decade has been in supporting inclusive environments in children's and youth programs in the community. I am hopeful that you will support my efforts to complete the work that is so important to me and has direct implication for all out-of-school-time programs, as there has been very little attention to the inclusion of children with disabilities in those programs.

My research proposal is intended to examine if there are differences in the perceptions of individuals in an organization as to how well the organization is doing in terms of including children with disabilities. We know that inclusion is in fact a *process and not a product* or outcome. We have learned that all organizations whether they are for profit or not for profit are someone along a developmental continuum in relation to the inclusion of individuals with disabilities. I have adapted a survey tool that was used to examine diversity initiatives in higher education and have created a survey tool that expands the definition of diversity to include ability differences.

The survey is called the Organizational Developmental Model of Inclusion for Individuals with Disabilities (ODMI – IWD). It is a *self-reflection questionnaire* that measures perceptions of people involved in the organizational process. There are no "right" or "wrong" answers and each respondent's answer will reflect *their perception* of how the organization responds to including people with disabilities. The survey will not assess or evaluate where your organization is on the developmental continuum but only what individual's perceptions are about where the organization is on a developmental continuum.

For purposes of keeping the sample population similar, I am proposing to survey four groups of individuals in each of 5 different Boys & Girls Clubs in Southern California, mostly in San Diego County. I am requesting that as Executive Director of The Boys & Girls Club of _____ will be agree to be one of the clubs in my study.

Your cooperation will involve the following. I would like to administer the survey to four groups of individuals (stakeholders) in the organization. They include the following groups:

- ☐ Management and Leadership including the Board of Directors
- ☐ All full time staff in the organization (defined as 30 hours or more/week)
- ☐ Parents of children with disabilities who are or have been involved in activities and programs at the club
- ☐ Parents of typically developing children who are or have been co-enrolled in activities at the same time as the children with disabilities.

The Survey involves answering a series of 50 questions and will take approximately 15 -20 minutes for participants to respond. I look forward to hearing from you soon so that I can give you specific details about how and when I would like to disseminate the surveys. You can call me at (541) 610-9182 or email me at mmcsheal309@aol.com if you have any questions about the study or the timeline. You may also contact my advisor Dr. Fred Galloway at the University of San Diego if you have questions for him. He can be reached at Galloway@sandiego.edu.

I very much appreciate your willingness to commit your organization to this research study. I passionately believe that the benefits of organizational self-reflection will vastly outweigh the small amount of time it takes to survey stakeholders regarding their beliefs about the level of organizational inclusiveness. No doubt the five organizations that complete this organizational self-reflection will become models for other organizations who wish to begin the process of including people with disabilities.

Sincerely,

Mary McAllister Shea
Ed. D. Candidate
University of San Diego

Appendix B

Organizational Developmental Model of Inclusion for Individuals with Disabilities Survey Tool

*ORGANIZATIONAL DEVELOPMENTAL MODEL
OF INCLUSION
FOR INDIVIDUALS WITH DISABILITIES
SURVEY TOOL*

Directions: Please Answer all items

For the following statements please rate your level of agreement with each statement, from 1 (Strongly Agree) to 5 (Strongly Disagree).

If you are unsure of the question or feel you can not respond, please circle the middle response (3).

SECTION ONE

1. In this organization, there are few, if any, individuals with disabilities in leadership or supervisory positions.

Strongly Agree Strongly Disagree
1-----2-----3-----4-----5

2. This organization is not interested in changing its organizational diversity in regard to the presence or absence of individuals with disabilities.

Strongly Agree Strongly Disagree
1-----2-----3-----4-----5

3. Individuals with disabilities are recruited to meet a quota or for this organization to “look good”.

Strongly Agree Strongly Disagree
1-----2-----3-----4-----5

4. Individuals with disabilities are expected to fit in with the organizational culture and expected to conform to the organization’s way of doing business or behave in certain ways.

Strongly Agree Strongly Disagree
1-----2-----3-----4-----5

5. In this organization, the number of individuals with disabilities who are members or employees does not resemble the 10% ratio of people with disabilities in the community.

Strongly Agree Strongly Disagree
1-----2-----3-----4-----5

6. Few, if any, efforts are made in this organization to recruit individuals with disabilities as employees or as board members.

Strongly Agree Strongly Disagree
1-----2-----3-----4-----5

7. Few, if any, efforts are made in this organization to recruit individuals with disabilities as members or customers.

Strongly Agree **Strongly Disagree**

1-----2-----3-----4-----5

8. Individuals with disabilities do not have an opportunity to express their views and advance within this organization.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

9. Opinions from individuals with disabilities or their families are not valued or encouraged.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

10. Natural representation of individuals with disabilities (at least 10%) is not an organizational expectation.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

SECTION TWO

1. Individuals with disabilities are treated differently in this organization.

Strongly Agree **Strongly Disagree**

1-----2-----3-----4-----5

2. The leadership in the organization is unaware of or unwilling to accept the existence of differential treatment of individuals with disabilities within the organization.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

3. There is no policy to respond to instances of differential treatment of individuals with disabilities within the organization.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

4. Leadership only confronts the issue of differential treatment of individuals with disabilities when prompted by external factors such as the threat of a lawsuit, criticism or negative publicity.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

5. Antidiscrimination policies regarding individuals with disabilities exist but are not consistently enforced.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

6. This organization is not responsive to forms of discrimination against individuals with disabilities.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

7. This organization does not openly address instances of differential treatment of individuals with disabilities.

Strongly Agree 1-----2-----3-----4-----5 Strongly Disagree

8. This organization does not actively monitor nor respond to forms of differential treatment of individuals with disabilities at all levels of the organization, including members or customers, employees or board members).

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

9. There is not a clear message that this organization will not tolerate discrimination against individuals with disabilities.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

10. Leadership and supervisors are not expected to enforce policies that discriminate against individuals with disabilities.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

SECTION THREE

1. This organization does not address the issue of diversity and the inclusion of individuals with disabilities.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

2. In this organization issues regarding diversity, particularly including individuals with disabilities, have been seen as "headaches" to be dealt with only when necessary.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

3. This organization addresses issues of diversity and the inclusion of individuals with disabilities only because of external pressures such as the threat of a lawsuit or public criticism.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

4. Problems and issues related to individuals with disabilities and discrimination against them are only seen as isolated incidents.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

5. This organization has developed a few "token programs" or initiatives to address the issue of including individuals with disabilities.
- Strongly Agree Strongly Disagree
1-----2-----3-----4-----5
6. Norms and values regarding the inclusion of individuals with disabilities are not clearly articulated nor are they disseminated throughout the organization.
- Strongly Agree Strongly Disagree
1-----2-----3-----4-----5
7. This organization has not implemented a plan to create an environment where individuals with disabilities are welcomed and included.
- Strongly Agree Strongly Disagree
1-----2-----3-----4-----5
8. This organization is not able to recognize incongruencies between expressed values and organizational behavior.
- Strongly Agree Strongly Disagree
1-----2-----3-----4-----5
9. Management and leadership, including the board of directors, are not held accountable for policies or practices that discriminate against individuals with disabilities.
- Strongly Agree Strongly Disagree
1-----2-----3-----4-----5
10. This organization addresses issues of diversity and the inclusion of individuals with disabilities only because of possible incentives such as additional program funding or to secure outside resources.
- Strongly Agree Strongly Disagree
1-----2-----3-----4-----5

SECTION FOUR

1. This organization has no desire or motivation to change regarding issues of diversity, specifically, the inclusion of individuals with disabilities.
- Strongly Agree Strongly Disagree
1-----2-----3-----4-----5
2. In this organization, issues of discrimination against individuals with disabilities are denied.
- Strongly Agree Strongly Disagree
1-----2-----3-----4-----5
3. In this organization, issues of diversity and discrimination against individuals with disabilities are minimized.
- Strongly Agree Strongly Disagree
1-----2-----3-----4-----5

4. Fear of external events, like the threat of a lawsuit or negative publicity, is the motivation for this organization to change its practices regarding diversity and the inclusion of individuals with disabilities.

Strongly Agree

Strongly Disagree

1-----2-----3-----4-----5

5. Opportunities to take advantage of additional funding, or available resources is a motivation for this organization to include individuals with disabilities.

Strongly Agree

Strongly Disagree

1-----2-----3-----4-----5

6. This organization does not welcome or promote the inclusion of individuals with disabilities.

Strongly Agree

Strongly Disagree

1-----2-----3-----4-----5

7. This organization does not perceive the inclusion of individuals with disabilities as valuable.

Strongly Agree

Strongly Disagree

1-----2-----3-----4-----5

8. Natural ratios of individuals with disabilities (approximately 10%) are not perceived as the goal to create a more diverse and inclusive membership in the organization.

Strongly Agree

Strongly Disagree

1-----2-----3-----4-----5

9. Orientation for new members or customers does not include sharing the organization's philosophy of including individuals with disabilities.

Strongly Agree

Strongly Disagree

1-----2-----3-----4-----5

10. Policies and procedures regarding the inclusion of individuals with disabilities do not seem to be a part of the formal organizational orientation for members or customers or staff or board members.

Strongly Agree

Strongly Disagree

1-----2-----3-----4-----5

SECTION FIVE

1. Individuals with disabilities might be present in the organization but they are really invisible and do not seem to have a voice in the organization.

Strongly Agree

Strongly Disagree

1-----2-----3-----4-----5

2. In this organization individuals with disabilities experience differential treatment.

Strongly Agree

Strongly Disagree

1-----2-----3-----4-----5

3. In this organization individuals with disabilities seem to feel powerless.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5
4. In this organization, individuals with disabilities are present in small numbers or are over represented in lower level positions like maintenance/housekeeping or support level jobs and not in higher level paid positions or leadership positions.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5
5. Individuals with disabilities are isolated within this organization or alone much of the time.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5
6. Individuals with disabilities are expected to conform to other groups within the organization.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5
7. Individuals with disabilities within the organization can not voice important issues of power and diversity and inclusion.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5
8. Individuals with disabilities do not have expectations that the organization will recognize all forms of differential treatment and respond to their needs.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5
9. There are significant differences in degree of involvement in the organization between individuals with disabilities and other members of the organization.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5
10. Individuals with disabilities do not have equal access to resources and opportunities within the organization.

Strongly Agree Strongly Disagree

1-----2-----3-----4-----5

Thank you for taking the time to complete this survey. By completing and returning the survey you consent to having the results anonymously included in the research study.

Appendix C

Organizational Developmental Model of Inclusion For Individuals with Disabilities Electronic Survey Form

Directions: Please answer ALL ITEMS.

For the following statements please rate your level of agreement with each statement, from 1 (Strongly Agree) to 5 (Strongly Disagree)

If you are unsure of the answer or feel you can not respond, please circle the middle response.

At times the questions may seem repetitive; however they are intended to elicit specific responses so please read each one carefully and complete all questions.

1. In this organization, there are few, if any, individuals with disabilities in leadership or supervisory positions

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

2. This organization is not interested in changing its organizational diversity in regard to the presence or absence of individuals with disabilities

Strongly Agree

Agree

Unsure

Disagree

Strongly
Disagree

3. Individuals with disabilities are recruited to meet a quota or for this organization to "look good"

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

4. Individuals with disabilities are expected to fit in with the organizational culture and expected to conform to the organization's way of doing business or behave in certain ways

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

5. In this organization, the number of individuals with disabilities who are members or employees does not resemble the 10% ratio of people with disabilities in the community

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

6. Few, if any, efforts are made in this organization to recruit individuals with disabilities as employees or board members

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

7. Few, if any, efforts are made in this organization to recruit individuals with disabilities as members or customers

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

8. Individuals with disabilities do not have an opportunity to express their views and advance within this organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

9. Opinions from individuals with disabilities or their families are not valued or encouraged

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

10. Natural representation of individuals with disabilities (at least 10%) is not an organizational expectation

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

11. Individuals with disabilities are treated differently in this organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

12. The leadership in the organization is unaware or unwilling to accept the existence of differential treatment of individuals with disabilities within the organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

13. There is no policy to respond to instances of differential treatment of individuals with disabilities within the organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

14. Leadership only confronts the issue of differential treatment of individuals with disabilities when prompted by external factors such as the threat of a lawsuit, criticism or negative publicity

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

15. Antidiscrimination policies regarding individuals with disabilities exist but are not consistently enforced

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

16. This organization is not responsive to forms of discrimination against individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

17. This organization does not openly address instances of differential treatment of individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

18. This organization does not actively monitor nor respond to forms of differential treatment of individuals with disabilities at all levels of the organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

19. There is not a clear message that this organization will not tolerate discrimination against individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

20. Leadership and supervisors are not expected to enforce policies that discriminate against individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

21. This organization does not address the issue of diversity and the inclusion of individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

22. In this organization issues regarding diversity, particularly including individuals with disabilities, have been seen as "headaches" to be dealt with only when necessary

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

23. This organization addresses issues of diversity and the inclusion of individuals with disabilities only because of external pressures such as the threat of a lawsuit or public criticism

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

24. Problems and issues related to individuals with disabilities and discrimination against them are only seen as isolated incidents

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

25. This organization has developed a few "token programs" or initiatives to address the issue of including individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

26. Norms and values regarding the inclusion of individuals with disabilities are not clearly articulated nor are they disseminated throughout the organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

27. This organization has not implemented a plan to create an environment where individuals with disabilities are welcomed and included

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

28. This organization is not able to recognize incongruencies between expressed values and organizational behavior

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

29. Management and leadership, including the board of directors, are not held accountable for policies or practices that discriminate against individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

30. This organization addresses issues of diversity and the inclusion of individuals with disabilities only because of possible incentives such as additional program funding or to secure outside resources

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

31. This organization has no desire or motivation to change regarding issues of diversity, specifically, the inclusion of individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

32. In this organization, issues of discrimination against individuals with disabilities are denied

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

33. In this organization, issues of diversity and discrimination against individuals with disabilities are minimized

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

34. Fear of external events, like the threat of a lawsuit or negative publicity, is the motivation for this organization to change its practices regarding diversity and the inclusion of individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

35. Opportunities to take advantage of additional funding or available resources is a motivation for this organization to include individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

36. This organization does not welcome or promote the inclusion of individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

37. This organization does not perceive the inclusion of individuals with disabilities as valuable

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

38. Natural ratios of individuals with disabilities (approximately 10%) are not perceived as the goal to create a more diverse and inclusive membership in the organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

39. Orientation for new members or customers does not include sharing the organization's philosophy of including individuals with disabilities

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

40. Policies and procedures regarding the inclusion of individuals with disabilities do not seem to be a part of the formal organizational orientation for members or customers or staff or board members

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

41. Individuals with disabilities might be present in the organization but they are really invisible and do not seem to have a voice in the organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

42. In this organization individuals with disabilities experience differential treatment

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

43. In this organization individuals with disabilities seem to feel powerless

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

44. In this organization, individuals with disabilities are present in small numbers or are over-represented in lower level positions like maintenance, housekeeping or support level jobs and not in higher level paid positions or leadership positions

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

45. Individuals with disabilities are isolated within the organization or alone much of the time

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

46. Individuals with disabilities are expected to conform to other groups within the organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

47. Individuals with disabilities within the organization can not voice important issues of power, diversity and inclusion

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

48. Individuals with disabilities do not have expectations that the organization will recognize all forms of differential treatment and respond to their needs

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

49. There are significant differences in degree of involvement in the organization between individuals with disabilities and other members of the organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

50. Individuals with disabilities do not have equal access to resources and opportunities within the organization

Strongly
Agree

Agree

Unsure

Disagree

Strongly
Disagree

51. Please state which Boys & Girls Club You represent

- 1) Boys & Girls Club of
- 2) Boys & Girls Clubs of
- 3) Boys & Girls Club of
- 4) Boys & Girls Clubs of
- 5) Boys & Girls Clubs of

52. Please mark the stakeholder group you represent

- 1) Board of Directors
- 2) Management Staff
- 3) Program Staff
- 4) Parent of Typically Developing Child
- 5) Parent of a Child with a Disability

53. Please check the consent below if you agree to have your responses included in the survey results

- 1) Yes, you may use my responses
- 2) No, you may not use my responses

Appendix D

Letter to Board, Leadership and Staff

Date _____

Dear _____

I am writing to ask your support in a research study that will examine the perceptions of program staff, management, leadership and membership of the organization, defined as parents of children at a number of Boys & Girls Clubs in California. You are receiving this letter of request because you were not in attendance at the board meeting and/or the staff meeting when the survey was introduced and distributed to board and staff.

I am a doctoral student completing my dissertation at the University of San Diego's School of Education. I have over 25 years experience working with children with disabilities and their families and have spent the last 10 years supporting organizations that work with children with disabilities in inclusive environments and settings in after school programs and other child care activities. There is a lack of research in the area of inclusion of children with disabilities in out-of-school-time programs and I have chosen the Boys and Girls Clubs as one example of youth programs that have begun the process of welcoming and including children with disabilities.

I am asking for your support and cooperation to complete the enclosed survey and return in to me in the self-addressed stamped envelope by March 15th, 2005. The survey is a tool that will assist organization in determining where they are on a developmental continuum in their efforts to include and support children with disabilities and their families. Your answers are strictly confidential and no other persons in the organization will see you responses, although the results of the overall research project will be shared with anyone interested.

The survey will take approximately 12-15 minutes to complete. At times the questions may seem repetitive; however they are intended to elicit specific responses to specific questions so please read each question carefully. It is important that you answer all questions on the survey as well as complete all demographic data on the questionnaire. Finally, please be careful to circle your answers correctly.

Thank you very much for completing and returning this survey to me. By completing and returning the survey you have consented to use the information in my research study.

Do not hesitate to contact me by phone or email if you have any questions or concerns about completing the survey. I can be reached at (541) 610-9182 or by email mmcshea1309@aol.com

Sincerely,

Mary Shea
Ed .D. Candidate
University of San Diego School of Education

Appendix E
Letter to Parents

Date _____

Dear Parent _____

I would like to introduce myself and tell you why I am writing to you. I am a graduate student at the University of San Diego in the School of Education and am completing my dissertation for a doctoral degree in Leadership Studies. I have over 25 years experience working with children with disabilities and their families and have spent the last 10 years supporting organizations that work with children with disabilities in inclusive after school programs. I am very passionate about children with disabilities and their families and I am sure the information we learn from this research study will assist other families of children with disabilities as well as the organizations that are welcoming and supporting them.

I am asking for your support and cooperation to complete the enclosed survey, including the last page, which includes demographic questions. I would ask you to return the survey to me in the self-addressed stamped envelope by July 10th. The survey is a tool that will assist organizations in determining where they are in the developmental process in their efforts to include and support children with disabilities and their families. **Your answers are strictly confidential** and none of the staff or leadership in the organization, or even other parents will see your responses, although the results of the overall research project will be shared with anyone interested.

The survey will take approximately 15-20 minutes to complete. At times the questions may seem repetitive; however they are intended to elicit specific responses to specific questions so **please read each question carefully**. It is important that you **answer all questions** on the survey as well as complete all demographic data on the questionnaire. Finally, please be careful to circle your answers correctly.

Thank you very much for completing and returning this survey to me. I realize that you are very busy and have other priorities in your life. As a small token of my appreciation I have enclosed a one-dollar bill for completing the survey. Do not hesitate to contact me by phone or email if you have any questions or concerns about completing the survey. I can be reached at (541) 610-9182 or by email mmcshea1309@aol.com. You may also call or email my advisor Dr. Fred Galloway at the University of San Diego if you have questions for him about the research. He can be reached at (619) 260-7435 or by email galloway@sandiego.edu. Thank you very much for your help.

By completing and returning the survey you have given consent to me to use the information collected for my research study. Thank you very much for your help.

Sincerely,

Mary Shea
Ed .D. Candidate
University of San Diego School of Education